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**Up Front**

5 Editorial
Advances in Knowledge Benefit the PI Community
By Ronale Tucker Rhodes, MS

6 Abbie’s Corner
Beware of Copay Accumulator Programs
By Abbie Cornett

7 Faces of IG
From our Facebook page
By Abbie Cornett

**Departments**

8 Ask the Experts
Healthcare professionals’ responses to patient questions

9 Immunology 101
Blood Testing Issues for PI Patients, Part 3
By Terry O. Harville, MD, PhD

10 Therapeutic Helpline
Evaluating How Couples Are Impacted by Chronic Illness
By Erika Lawrence, PhD, LCP

12 Clinical Brief
Managing Side Effects of IVIG
By Michelle Greer, RN, and Leslie J. Vaughan, RPh

16 In the News
Research, science, product and insurance updates

**Features**

18 Genetic Testing for Immune Deficiencies and Autoimmune Disorders: A Patient Primer
By Troy R. Torgerson, MD, PhD

26 Sleep and the Immune System Link
By Jim Trageser

30 Harnessing the Power of the Mind Through Images
By Meredith Whitmore

34 Benefitting from Chronic Illness Insurance
By Abbie Cornett

37 Care Strategies for Peripheral Neuropathy
By Matthew D. Hansen, DPT, MPT, BSPTS

**Sources**

46 Product Guide
Sleep Disorders: When Counting Sheep Isn’t Enough
By Heather Bremner Claverie

48 Book Corner
New and useful reading

50 Resource Center
Community foundations, associations, forums and other resources

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SINCE THE FIRST primary immunodeficiency disease (PI) was described in 1952, some exciting advances have been made that are providing PI patients and clinical immunologists with a great deal of hope. Not only do we have greater knowledge about the different types of PI diagnoses, but their cause can now be more precisely pinpointed. While it has long been known most PIs are inherited, it has only been in the past 25 years that scientists have discovered specific gene mutations.

Troy R. Torgerson, MD, PhD, author of our article “Genetic Testing for Immune Deficiencies and Autoimmune Disorders: A Patient Primer” (p.18), explains why understanding the genetic mutation causing PIs and autoimmune disorders is so beneficial. For starters, he explains, it assists in making a definitive diagnosis. But, even more importantly, it guides treatment decisions, provides insurance justification and, for those concerned about passing the disorder onto children, assists with family planning. With newfound understanding of genetic testing, more types of sequencing approaches are available, which can make a difference based on patients’ symptoms and laboratory abnormalities. And, while in many cases insurance will cover the cost of genetic testing, the tests have become more affordable for those whose insurance won’t pay for it.

More is also being understood about how lifestyle can affect the immune system. Specifically, sleep plays a crucial role in maintaining good health, which is especially important for PI patients prone to infections. As we explain in our article “Sleep and the Immune System Link” (p.26), studies show lack of sleep impairs the body’s ability to effectively react to foreign microorganisms, making the body more vulnerable to infections. Research also shows people who don’t get adequate sleep are at higher risk of developing autoimmune disorders. And, while sleep disorders may be to blame for some people’s inability to sleep, it is more likely the cause is due to a lack of awareness and commitment to getting needed sleep.

It’s sometimes discounted how powerful a tool the mind is for healing the body. Indeed studies show the practice of guided imagery can alter the brain’s state, resulting in actual physiological changes as seen on functional MRIs. We explore how guided imagery, first studied and implemented in the 1970s, works in our article “Harnessing the Power of the Mind Through Images” (p.30). And, while it takes some practice to master, those who teach guided imagery say patients can use it to not only manage grief and reduce fear and stress, but also to manage chronic pain.

As always, we hope you enjoy these articles, as well as the many more educational and insightful topics presented in this issue of IG Living.

Ronale Tucker Rhodes, MS
Beware of Copay Accumulator Programs

By Abbie Cornett

**COPAY ACCUMULATOR programs**, which are being added by many insurance companies to their plans, represent the latest battleground between pharmacy benefit managers and drug manufacturers over the pricing of therapeutics, especially expensive specialty drugs. Payers argue copay accumulators were developed in response to manufacturers’ use of copay coupons to maintain high drug prices. On the other hand, manufacturers say copay coupons were necessary because payers increased copays and deductibles. Regardless of the reason for copay accumulators, they are going to directly impact patients’ ability to pay for their medications by significantly increasing out-of-pocket expenses.

Until recently, patients were able to use manufacturer medication coupons toward their deductibles. But, this will no longer be the case for patients who have plans that include a copay accumulator. This includes manufacturer copay assistance programs, copay cards and more traditional coupons many patients rely on to afford their medications.

Plans with copay accumulators will especially impact those with employer and Affordable Care Act insurance policies. Further, because these plans will directly affect how much a patient must pay out-of-pocket (OOP), copay accumulators are expected to disproportionately impact patients who are economically vulnerable and/or who are prescribed expensive medications.

The problems with copay accumulator plans stem from a lack of information. For instance, the effectiveness of an accumulator program is dependent on its being introduced prior to a determined treatment plan so patients and their physicians can discuss less-expensive or alternative treatments. To complicate matters, most companies are not notifying patients about changes in their coverage, making patient advocates worried patients will be caught off guard. Further, the policies’ language concerning the copay accumulator program is often confusing and is buried in the summary of benefits.

Patient Rising, a new advocacy group, recently published a story highlighting a patient who, after using his manufacturer coupons, found out they had not applied to his deductible. Consequently, his prescribed medication would cost him almost $5,000 a month. This amount was completely beyond his ability to pay. See the figure for an example of how a copay accumulator works.

In response to the threat these programs pose to the health and financial well-being of patients, Arizona, Virginia and West Virginia passed legislation that bans or significantly limits the programs. And, since the beginning of this year, multiple states have introduced bills to address the impact of accumulator programs on patients.

It is critical patients remain vigilant for any changes in insurance coverage and what they may mean to their ability to access treatment. Copay accumulator programs are just the latest fight in a long war. And, I can guarantee you they won’t be the last!

ABBIE CORNETT is the patient advocate for *IG Living* magazine. She can be reached at patient advocate@igliving.com or (800) 843-7477 x1366.

**References**


A ll medications, with the exception of those meant for women alone, are studied and tested on men first. We know that heart attacks in women are misdiagnosed or diagnosed later because [only men’s] signs are taught to medical students and doctors.

— Connie K

[No,] because even though “female hysteria” is a diagnosis from the past, it’s really not. It took me nine years [of] asking every doctor I had ever met “Do you know what’s wrong with me?” before I found the magic one who not only believed me, but actually knew what it was. I was born this way and [wasn’t] diagnosed with common variable immunodeficiency [until I was] 33 years old!

— Amber Q

Are you surprised that women are typically diagnosed later than men?

Have you received a surprise medical bill?

Yep, all the time, and I have to continually call and get things appealed and reversed and talk to [the insurance company] and doctors, etc. I do it because I can’t afford to pay bills that are wrong.

— Rachel D

Yes, I have received a surprise bill many times. Unfortunately, it takes a lot of time and energy to get it straightened out. Being a person whose health is fragile due to autoimmune/neuromuscular disease, it takes a toll. Sadly, it’s usually an error that could be resolved, but I’m sure there is a lot of red tape the insurance companies have to go through. And, calling the insurance company, I never get the same person. Very frustrating.

— Judy S

How do you dispose of your used medications?

When I had to do intravenous antibiotics for a month at home after having sepsis, I had a bunch of extra unopened syringes of heparin, saline flushes and a few of the antibiotics. Everyone, including the pharmacy, told me to just pitch them in the trash! Ah, no! Thankfully, the Humane Society took it all and put it to good use.

— Donna G

I drop it off at the local police station. They have a year-round medication take-back bin inside the station.

— Melanie C

I don’t flush them anymore. To be honest, I don’t often have unused medicines. I do have one that I need to dispose of properly, and I think there is a take-back [program] next weekend. It’s thalidomide and has to be handled properly due to serious birth defects, and I would be devastated if I caused that. I have tried several avenues to send it back, and no one will take it.

— Becki L
Abbie » It sounds like you may have developed aseptic meningitis from your infusion. Unfortunately, the only treatment for that is supportive such as hydration, pain medications and time. Before switching to another brand of IVIG, you might also try other approaches such as adding hydration, modifying premedications and slowing the infusion rate. If none of these approaches work, a brand change could be considered, but these side effects are possible with any brand of IVIG. Another option is to switch to subcutaneous IG therapy that causes fewer side effects overall.

Question » Is there a brand of IVIG that causes fewer side effects than others?

I just had my first intravenous immune globulin (IVIG) infusion three weeks ago, and I have been experiencing disabling side effects. I was administered Gammagard over two days for six to seven hours each. Since then, I have had horrible neck, spine and lower back pain, and my headache has gotten even worse. I am wondering if there is a brand of IVIG that tends to give people fewer side effects.

Question » What can be done to reduce the side effects from IVIG to treat CIDP?

I have chronic inflammatory demyelinating polyneuropathy (CIDP), and I have been treated with intravenous immune globulin (IVIG) for two years now. Although IVIG is a miracle drug, I have an extremely adverse reaction to it. I am infused three times per month, but to avoid emergency room visits from the 10-scale pain, which sometimes occurs anyways, the IVIG is infused over four days each time. I need to take an average of 300 mg of Benadryl, 4,000 mg of Tylenol, 2,400 mg of ibuprofen, and I drink more than two gallons of Pedialyte each day to lessen the reaction. I also take 40 mg of Toradol for three days, and even then, I am stuck in the dark for days due to pain. My doctor has tried everything: reducing the amount of IVIG, steroids, IV Benadryl and Ativan, slowing the infusion rate and extra IV fluids. Is there any other advice you can give?

Abbie » One of our experts recommends you discuss with your physician the possibility of switching to subcutaneous IG from your current IVIG treatment. This might be an option depending on the dose of IG you require. We addressed the use of SCIG for CIDP in the December-January 2019 issue of IG Living. SCIG therapy delivers a similar quantity of IG as IVIG over the same three- or four-week period. For example, a common twice-weekly SCIG infusion schedule divides a monthly IVIG dose into eight much smaller doses, causing the serum IgG peak level following each of these small subcutaneous infusions to be moderated by its relatively slow absorption into the bloodstream. A combination of small divided doses and slow absorption appears also to reduce both the incident and severity of headaches and nausea.

Have a question? Email us at editor@IGLiving.com. Your information will remain confidential unless permission is given.
WHEN TESTING patient blood for infection, nucleic acid testing (NAT) offers potentially better and more exact detection of various microorganism pathogens, especially in patients with primary immunodeficiencies (PIs) and those receiving immune globulin (IG) replacement therapy. NAT detects infectious pathogens even though PI patients lack the ability to make appropriate antibodies to them. Further, NAT can prevent misidentification of pathogens due to positive test results from antibodies received via IG replacement therapy derived from plasma of donors infected by those pathogens. Indeed, it’s possible for patients on IG replacement therapy to test positive for developing an infection when they don’t have one; in reality, these positive test results for infection are due to antibodies acquired from plasma donors who had been infected previously. Consequently, routine tests that rely on the detection of antibodies are unreliable for PI patients and those on IG replacement therapy.

As we discussed in the previous column, one major drawback to NAT is it is so sensitive that a virus, bacterium or fungus may be detected even if is not causing problems. For example, many individuals have been previously infected with Epstein Barr virus (EBV), which integrates its viral DNA into the host human genomic DNA of the infected cells. Once integrated, it can remain there in perpetuity. Thus, even if the virus is not causing an active infection, the viral DNA that remains may be detected by NAT. Being prepared for such a misleading result means treating physicians must use good clinical judgment about whether a detected potential pathogen requires treatment. Generally, physicians evaluate the magnitude of the detected viral DNA or increases in the amount of viral DNA from a previous test, which is known as a “copy number.” If a person had an EBV infection as an adolescent and is now having problems as an adult, the EBV viral load copy number can be indicative as to whether it represents only the dormant DNA integrated into the genomic DNA or whether it represents newly replicating viral DNA. Another approach is to use serum or plasma to look for the viral DNA since this is more likely to come from viral particles of replicating virus than from DNA found in the host genomic DNA, which would be found in people’s cells but not their plasma.

Another consideration with NAT is most forms of the test use “target nucleic acid sequences” (DNA or RNA) from a specific microorganism to identify that microorganism. Therefore, physicians need to have search criteria for microorganisms. This process is very different from a “culture assay” in which physicians merely look to see what grows out of the general growth media. NAT can only identify the assay components being tested. While there are panels of microorganisms for NAT detection available, these will not have all potential microorganisms possible. For example, if mycoplasma is causing pneumonia, but only microorganisms such as Pneumococcus, Klebsiella, E. coli and Haemophilus are being tested in the respiratory panel, then the microorganism causing the infection will be missed. To be sure, insightful clinical judgment must be part of ordering tests to provide useful results. It’s important that physicians recognize that PI patients may have infections from less-common organisms or from opportunistic infections. Therefore, a larger more comprehensive test panel is typically required. Further, physicians may need to evaluate for viruses, bacteria and fungi to be able to identify the infection culprit.

We will continue our discussion of NAT in PI patients and those on IG replacement therapy in the next issue.

TERRY O. HARVILLE, MD, PhD, is medical director of the Special Immunology Laboratory at the University of Arkansas for Medical Sciences and a consultant for immunodeficiencies, autoimmunities and transplantation.
CHRONIC ILLNESS TAKES an ongoing toll on a relationship. Although all couples have rough times, those faced with a chronic illness endure even more. These extra challenges can lead to increased conflict or problems in supporting each other. Based on decades of research and couples therapy, following are four areas where relationships under stress of illness may require attention.

Emotional Intimacy
When you are in pain, ill or stressed out, it’s easy to forget to take care of the emotional intimacy in your relationships. However, even when you are too tired or too sick to do anything active, you can still express care, love and affection. Here are questions to consider to determine whether there is emotional intimacy in your relationship:

• Closeness: How close do you feel to your partner? Is there a sense of warmth and affection? Do you enjoy spending time together? Do you feel emotionally connected?
• Trust: Do you trust each other? Do you trust your partner won’t lie to you, or betray, abandon or hurt you when things get tough? Do you trust the bond between you is still there even if you aren’t around each other?
• Friendship: Is your partner one of your closest friends? Do you have fun together? Do you like to spend your free time together?
• Emotional vulnerability: Are you able to confide in each other? Can you share uncomfortable emotions (embarrassment, shame, guilt, insecurities)?
• Affection: Do you express love and affection for each other in ways that are appreciated? This may be verbal (saying I love you) or nonverbal (giving hugs and kisses).

Support
Having a chronic illness means you may need more support than you can provide at times. It can be especially hard to be there for someone else on days when you are really feeling ill. That just means it is important to provide support on your better days. Here are questions to ask yourself to determine whether the support aspect of your relationship is strong.

• Solicitation: Do you ask for the help you need — physically or emotionally? Are you clear about the type of support you want in the moment (help fixing the problem vs. listening quietly to you vs. giving you space)? Do you forgive yourself for needing more support on your “bad” days or during flare-ups?
• Provision: Do you provide support when it’s requested (or when you notice the other person needs it)?

Evaluating How Couples Are Impacted by Chronic Illness
By Erika Lawrence, PhD, LCP
• Adequacy: Do you provide the type of support your partner wants (which may be different than what you would want)?

• Mutuality: There are always times when one person needs more support than the other. However, over time, does it balance out?

Respect and Control

Having a chronic illness may leave you feeling as if you have little control in your life or in your relationship. You may feel the illness has all the control. Nevertheless, it is important to remember to treat each other with respect and acceptance even when you’re angry or anxious.

• Respect: Do you treat each other as competent, independent adults (vs. as children)? Do you treat each other with respect even when you disagree or are upset with each other?

• Acceptance: Do you accept each other’s hobbies, passions, careers and habits? Or, do you make spiteful or belittling comments?

• Decision-making: Are you both satisfied with how major decisions get made? Decision-making does not have to be 50/50. It is more important that both partners are happy with how decisions get made.

• Control: Do each of you have the freedom to spend time with family and friends, to pursue your goals and to schedule your own days? Obviously, no one has complete freedom if they have a family. Checking with your partner out of respect is different from not being allowed to see a friend because your partner will be angry.

• Red flags: If your partner is isolating you socially or financially, these are red flags.

Conflict

All couples have disagreements and differences of opinion. What matters is how you behave during those arguments and how you recover from them afterward. Here are questions to help you determine whether you need more skills in this area.

• During arguments: Are you able to disagree without putting each other down? Are you able to get angry without being mean or hurtful? If you decide to take a break because things are getting too heated, do you come back together to finish the discussion once you’ve both calmed down?

• Recovery: How couples recover from arguments can protect them from the negative affects of conflict. Do you revisit the argument once you’ve both calmed down? Do you get to a resolution or at least agree to disagree? Do you each apologize for anything hurtful that you said or did during the argument?

• Red flags: Of course, it is never acceptable to put your hands on the other person, try to scare them or be cruel.

Making Improvements

All couples have strengths, as well as areas that need growth. As you read this, there are probably areas in which the two of you really shine. Good for you! There are also probably one or two areas in which the two of you could improve. This is also normal and to be expected. None of us know exactly how to shine in every area of our relationship. For example, if you did not grow up with parents who demonstrated healthy emotional intimacy, why should you be expected to be good at it?

The good news is these are skills you can learn and areas that you can improve upon. The first step may be going through this list together to evaluate where your strengths lie and where you could improve. Then, start to be mindful of the areas that could use some more work. And, remember, all relationships fluctuate and all couples have strengths and challenges. The trick is to weather them together and take a long perspective.

ERIKA LAWRENCE, PhD, LCP, is director of translational science at The Family Institute at Northwestern University, Evanston, Ill.

Even when you are too tired or too sick to do anything active, you can still express care, love and affection.
Managing Side Effects of IVIG

By Michelle Greer, RN, and Leslie J. Vaughan, RPh

INTRAVENOUS IMMUNE globulin (IVIG) is a very effective treatment that frequently provides disease improvement for people who have suffered years of misdiagnosis and medications that did not help. For some people such as those with primary immunodeficiency, IVIG therapy is the only treatment for their condition. But, because IVIG evokes an immune response, side effects can be expected. Fortunately, there are ways to mitigate and even eliminate them. Additionally, there are more serious reactions that are rare, so it’s imperative to understand what these are and how to take steps to decrease their occurrence. It’s also important to ensure nurses who administer IVIG have received education and training on how to safely and effectively infuse IG. Following are the potential side effects of IVIG and how to mitigate them to ensure tolerability and long-term success.

Side Effects of IVIG

The most common reactions to IVIG are flu-like symptoms, including headache, fatigue, body aches and fever. Headache is the most commonly reported side effect, with pain ranging from mild to severe. For most people, premedication with acetaminophen is routine, and if headache occurs, the dose may be repeated. People who experience frequent headaches or even migraines prior to starting IVIG may be at a higher risk for a more severe headache. In this case, steroids or the person’s current prescribed migraine treatment may also be given as pre-medication. A severe headache along with other symptoms such as nausea, vomiting and neck pain or stiffness can signal a more serious adverse reaction known as aseptic meningitis. If these symptoms are reported, the physician should be notified, and the person may need to seek emergency medical attention.

Blood pressure fluctuation is another potential side effect. If the person is known to have hypertension, it is especially important to take blood pressure medications exactly as prescribed. And, the nurse administering the IVIG should take a baseline blood pressure prior to starting the infusion. IVIG infusions are started slowly and ramped up at predetermined intervals.
to a maximum rate. Blood pressure should be monitored throughout the infusion, and is typically taken right before an increase in the rate of infusion. If at any point in the infusion the person does not feel well, blood pressure and other vital signs such as pulse, breathing rate and temperature should be reassessed. If blood pressure is high, the infusion should be paused and restarted when symptoms or blood pressure normalize. Many reactions can be resolved simply by slowing the rate or pausing the infusion and resuming when symptoms subside.

Studies have shown a rash or other dermatological reaction occurs in about 6 percent of persons treated with IVIG. The rash may present as redness, papules (small red bumps) and itching. This reaction does not necessarily indicate an allergic reaction, nor does it mean IVIG should be discontinued. Typically, in such instances, a premedication of steroids is added.

More severe reactions are rare, but a physician and/or pharmacist or nurse should perform a risk assessment prior to initiating treatment to formulate the best plan to prevent the reactions (Table 1). Additionally, people receiving IVIG should be educated about the potential for developing side effects so they will be aware of which signs and symptoms they should promptly report to the physician or pharmacist. These reactions can include aseptic meningitis, as mentioned earlier, as well as impaired renal function, thrombotic event and hemolytic anemia. Preventive measures can be instituted for these severe reactions; however, if these side effects occur, consideration may be given to changing the brand of IVIG (Table 2).

One of the most important ways to reduce side effects is to hydrate. Drinking an adequate amount of water several days prior to the infusion, on the infusion day and a few days after the infusion is key. Unless there is a clinical reason someone should not have increased fluids, the person should drink 64 ounces (8 cups) of water each day. Some physicians may prescribe intravenous fluids to be infused just prior to the IVIG infusion.

Table 1. Predisposing Factors for IVIG-Induced Adverse Effects

<table>
<thead>
<tr>
<th>Adverse Effect</th>
<th>Predisposing Factors</th>
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<tbody>
<tr>
<td>Flu-like symptoms</td>
<td>High dose, rapid infusion rate, accompanying infection, previous adverse effects</td>
</tr>
<tr>
<td>Dermatological adverse effects</td>
<td>High dose, rapid infusion rate, accompanying infection, male patients with chronic inflammatory demyelinating polyneuropathy</td>
</tr>
<tr>
<td>Arrhythmia and hypotension</td>
<td>History of heart disease</td>
</tr>
<tr>
<td>Transfusion-related acute lung injury</td>
<td>Rapid infusion rate</td>
</tr>
<tr>
<td>Thrombotic events</td>
<td>High dose, rapid infusion rate, advanced age, being bedridden, diabetes mellitus, hypertension, dyslipidemia, prior/current thrombosis, preexisting atherosclerotic disease, elevated serum viscosity, oral contraceptive use, hereditary hypercoagulable state, idiopathic thrombocytopenic purpura</td>
</tr>
<tr>
<td>Aseptic meningitis</td>
<td>High dose</td>
</tr>
<tr>
<td>Renal impairment</td>
<td>Rapid infusion rate, advanced age, renal insufficiency, nephrotic syndrome, diabetes mellitus, dehydration, sepsis paraproteinemia, nephrotoxic drugs, hemolysis, sucrose-containing preparations</td>
</tr>
<tr>
<td>Hemolysis</td>
<td>High dose, rapid infusion rate, non-O blood group, underlying inflammatory state</td>
</tr>
</tbody>
</table>
Prehydration with normal saline is also used to prevent IVIG-induced adverse effects. Many studies have proposed prehydration can be helpful to reduce the risk of headache, thrombolysis (blood clots), renal impairment (decreased kidney function) and hemolysis (destruction of red blood cells).1

If the potential for side effects is great, or if they have already occurred, the subcutaneous (SC) route of administration can be considered. With the exception of injection site reactions, side effects are generally much less frequent with SCIG. This is the case for lower doses typically given to immune deficiency patients and higher doses typically given to autoimmune disease patients. Recent studies have resulted in U.S. Food and Drug Administration-approved indications for SCIG therapy for chronic inflammatory demyelinating polyneuropathy, a neurological disease treated with much higher doses of IVIG. Since the incidence of many of the severe reactions occur with high-dose IVIG, the physician, patient and pharmacist can decide if SCIG might be preferable.

**A Safe Therapy**

All in all, IVIG is very safe, and many people tolerate this treatment with minimal or no side effects. For many side effects, simply slowing the rate of infusion can resolve them. In addition, compliance with premedication protocols is imperative, an appropriate risk assessment must be conducted prior to initiating therapy, and infusions must be tailored to the individual and administered by nurses who have proper training in IVIG therapy. Taking these steps will optimize tolerability and overall positive outcomes.

**Table 2. Preventive Measures for IVIG Side Effects**

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Risk Assessment</th>
<th>Preventive Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aseptic meningitis</td>
<td>History of migraines in conjunction with high-dose (2 gm/kg or greater) IVIG.</td>
<td>Slower infusion rate; adequate or consider prehydration; premedication with migraine medication and/or steroids.</td>
</tr>
<tr>
<td>Impaired renal function</td>
<td>Baseline renal function testing — creatinine results; history of renal dysfunction or failure; on dialysis; comorbidity or diabetes.</td>
<td>Ensure use of a 10% IVIG solution (more drug in less volume); slower infusion rate; routine monitoring of BUN and creatinine; careful blood pressure monitoring. Observe for any symptoms of renal impairment including:  • Decreased urine output  • Dark/tea-colored urine</td>
</tr>
<tr>
<td>Thrombotic event</td>
<td>History of blood clotting, including deep vein thrombosis, stroke, myocardial infarction and/or pulmonary embolism; smoker; poor mobility and decreased activity; coronary artery disease; large first dose.</td>
<td>Consider adding premedication of over-the-counter aspirin or a prescription anticoagulant, depending on risk.</td>
</tr>
<tr>
<td>Hemolytic anemia</td>
<td>Usually neither recognized nor treated because it lacks clinical symptoms. A common complication of high-dose IVIG derived from non-group O blood.1</td>
<td>Monitor blood values if needed. Observe for any symptoms of anemia, including:  • Fatigue, poor energy level  • Generalized weakness  • Pale skin  • Cold hands and feet  • Dizziness  • Rapid heart rate  • Shortness of breath</td>
</tr>
</tbody>
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**Reference**

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IN THE NEWS

Research

Study Shows SCIG 20% Well-Tolerated in Pediatric PI Patients

In a study to assess the safety and tolerability of relatively high infusion rates and volumes per site in a broad pediatric primary immunodeficiency disease (PI) patient population treated with subcutaneous immune globulin (SCIG) 20% (Cuvitru), researchers found it was well-tolerated. In the study, data were pooled from 50 patients younger than 18 years old from two Phase II/III studies conducted in North America (11 sites in the U.S. and Canada) and Europe (10 sites in five countries). The most common PI diagnosis was common variable immunodeficiency, followed by X-linked agammaglobulinemia.

The North American trial consisted of four study periods. In period one, all patients received intravenous immune globulin (IVIG) 10% for 13 weeks to determine the area under the curve for IgG after treatment. In periods two through four, patients received SCIG 20% to determine if systemic exposure was equivalent to the IVIG 10% treatment. In period two, an adjustment factor of 145 percent was approximated to calculate the SCIG 20% dose based on pharmacokinetic (PK) data from other SCIG products. In period three, all patients received the adjusted dose (145 percent of the IVIG 10% dose) for 12 weeks, and individual IgG trough levels were assessed. In period four, all patients continued to receive SCIG 20% for 40 weeks at an individually adapted dose.

The European trial consisted of two periods. During period one, patients received IVIG 10% for 13 weeks or SCIG 16% for 12 weeks to attain a stable baseline serum IgG and to assess IgG trough levels and the PK levels of IVIG 10% or SCIG 16% before starting SCIG 20% treatment. In period two, patients were treated with SCIG 20% for 52 weeks during which time IgG trough levels and PK levels were assessed.

Results showed relatively large infusion volumes up to 60 ml per site and fast infusion rates up to 60 ml per hour per site of SCIG 20% were well-tolerated in pediatric patients with low rates of causally related systemic and local adverse events. SCIG 20% administration also demonstrated the advantage of few needle sticks and short infusion duration, which may be of particular benefit in children with needle phobia or when infusion duration is a concern.


Medicines

IVIG Manufacturing Process for Bivigam Approved by FDA

ADMA Biologics has received approval from the U.S. Food and Drug Administration (FDA) for its prior approval supplement for Bivigam (immune globulin intravenous [human] 10% liquid), allowing the company to use its optimized intravenous immune globulin (IVIG) manufacturing process and market Bivigam to primary immunodeficiency patients in the U.S.

Bivigam was first approved by FDA in December 2012 and was then marketed by Biotest Pharmaceuticals Corp.; however, Biotest suspended commercial production of Bivigam due to manufacturing and compliance issues. Subsequent to ADMA’s acquisition of the Biotest Therapy Business Unit in June 2017, ADMA resumed production of Bivigam during the fourth quarter of 2017, successfully manufacturing three conformance lots using the company’s optimized IVIG manufacturing process. ADMA anticipates the relaunch of Bivigam for commercial sale during the second half of 2019.

“We are pleased to reintroduce Bivigam into the market, where demand for IVIG therapy continues to outpace supply,” said Adam Grossman, president and chief executive officer of ADMA. “The $6 billion U.S. market for IVIG continues to grow, and the relaunch of Bivigam can help to alleviate a portion of the tight supply for this important patient population where dependable and consistent supply of IVIG is critical to patients’ well-being.”

Insurance

New Medicare App Shows What Services Are Covered

The Centers for Medicare and Medicaid Services (CMS) has launched a new app that gives consumers a modernized Medicare experience with direct access on a mobile device to some of the most-used content on Medicare.gov. The new What’s Covered app lets people with Original Medicare, caregivers and others quickly see whether Medicare covers a specific medical item or service.

In addition to the What’s Covered app, through Blue Button 2.0, the agency is enabling beneficiaries to connect their claims data to applications and tools developed by innovative private-sector companies to help them understand, use and share their health data.

“eMedicare is one of several initiatives focused on modernizing Medicare and empowering patients with information they need to get the best value from their Medicare coverage,” said CMS Administrator Seema Verma. “President Trump is delivering on his commitment to Medicare by modernizing tools that deliver health information in the most convenient way possible. This new app is the next in a suite of products designed to give consumers more access and control over their Medicare information.”

CMS created the app to meet the needs of the growing population of people with Medicare, which is projected to increase almost 50 percent by 2030—from 54 million beneficiaries in 2015 to more than 80 million beneficiaries in 2030. As of 2016, about two-thirds of Medicare beneficiaries indicate they use the Internet daily or almost daily (65 percent).

Questions about what Medicare covers are some of the most frequent inquiries CMS receives. There are approximately 15 million page views annually for coverage-related content on Medicare.gov and (800) MEDICARE receives more than three million coverage-related calls each year.

CMS launched the eMedicare initiative in 2018 to empower beneficiaries with cost and quality information. Other tools in the eMedicare suite include:

- Enhanced interactive online decision support to help people better understand and evaluate their Medicare coverage options and costs between Medicare and Medicare Advantage;
- A new online service that lets people quickly see how different coverage choices will affect their estimated out-of-pocket costs;
- New price transparency tools that let consumers compare the national average costs of certain procedures between settings, so people can see what they’ll pay for procedures performed in a hospital outpatient department versus an ambulatory surgical center;
- A new webchat option in the Medicare Plan Finder; and
- New easy-to-use surveys across Medicare.gov so consumers can continue to tell Medicare what they want.

The What’s Covered app is available for free in both Google Play and the Apple App Store.

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Research

Informatics Could Help Diagnose PI and Save Money

A recent study shows population-wide informatics can help in detecting primary immunodeficiency disease (PI) and improve outcomes, thus saving money. In the study, researchers assessed individual risk for PI by analyzing diagnostic codes and pharmacy records from 185,893 members of a pediatric health network. Relevant infection-associated diagnostic codes were weighted and enumerated for individual members allowing for risk score calculations (risk vital sign). At-risk individuals underwent further assessment by chart review and reanalysis of diagnostic codes 12 months later. Findings showed of the original cohort, 2,188 (1.2 percent) individuals were identified as medium-high risk for having a PI. This group included 41 subjects who were ultimately diagnosed with PI. An additional 57 medium-high risk patients had coded diagnoses of PI recorded by the healthcare provider and referred for medical attention.

As genetic testing becomes more available, it is helpful for patients to understand what options are available and their benefits and risks.

By Troy R. Torgerson, MD, PhD
THE FIRST REPORT of a gene mutation causing an immune deficiency was published just more than 25 years ago. Since this initial report, there has been a rapid increase in the pace of new immunodeficiency-associated gene discoveries. At present, mutations in more than 400 different genes have been associated with disorders of the immune system. This growing number of identified gene defects has created hope among immunologists that they may eventually be able to provide a genetic diagnosis to virtually every patient who presents with a significant immune problem. The result is that gene sequencers have taken their place alongside the stethoscope and the CT scanner as critical tools of the trade for clinical immunologists.

The growing number of gene defects associated with immune disorders has broadened the scope of what is now considered to be an “immune deficiency.” Traditionally, the term was used to describe patients who had frequent, severe or unusual infections. Defects in the immune system were primarily in the cells or proteins required to attack invading bacteria, viruses or fungi. Over time, we have come to realize there are a growing number of genetic immunodeficiencies in which the main clinical problem is not infections, but severe, early-onset or unusual autoimmunity or inflammatory disease. The immune defects in these patients mostly affect the parts of the immune system that control the potency of an immune response or how long the response lasts. Without these control mechanisms in place, the immune system may react too strongly or may attack more than the invading viruses or bacteria, leading to autoimmunity and inappropriate inflammation.

Background and Definitions

Before proceeding with a more detailed discussion of genetic testing, its use in the immunology clinic and its risks and benefits, it will help to furnish some definitions that provide the background to understand this very useful tool.

DNA. DNA is made up of four nucleotides or “bases” represented by the letters A (adenine), T (thymine), G (guanine) and C (cytosine). The A, T, G and C bases are linked together to form the structure of DNA that is shaped like a very long ladder. Each side rail of the ladder is created as the A, T, G and C bases are connected to one another to form long strands. The sequence in which the bases are connected to one another “spells out” the genes and creates the genetic code. The rungs of the ladder are made as the bases on each of the side rails link to one another in a specific way: A linking to T (A-T) and C linking to G (C-G). If grasped at the ends and stretched out, the ladder of DNA in a single cell would be about 6 feet long. In order to stuff this into the nucleus of a tiny cell, the ladder is twisted into a helix and wound around proteins like thread around a series of spools to form chromosomes.

Chromosomes. The 6 feet of DNA from a single cell is divided into 46 pieces that are each packaged to become a chromosome by winding around a series of protein “spools” so they can all fit into the nucleus of a tiny cell. Each human cell has 46 chromosomes, 23 inherited from the father and 23 inherited from the mother. One of the chromosomes from each parent is an “X” or a “Y” chromosome that carries DNA sequences that determine the sex of the individual.
These are called the “sex” chromosomes. Females have two X chromosomes and males have one X and one Y chromosome.

**Genome.** The term “genome” refers to the DNA sequence that is included in one complete set of 46 chromosomes contained in a single human cell. The human genome consists of about 3.2 billion bases or “letters” that are linked together to form those 6 feet of DNA. To put this in perspective, this is the same number of letters contained in 1,000 copies of the English translation of Leo Tolstoy’s *War and Peace*, considered by most to be a very long novel. Mercifully, DNA is a much more efficient means of storing information than the printed page; otherwise, a single human cell would be enormous in both size and weight. When we refer to “whole genome sequencing,” it means the sequence of all 3.2 billion letters of DNA in the individual is determined.

**Exome.** Interestingly, it turns out only 1 percent of the human genome (10 copies of *War and Peace*) actually contains all of the sequences that make up the genes. These are contained in blocks of DNA sequence called “exons” that are linked together by intervening stretches of DNA that are not part of the genes. Originally thought to be “junk” DNA or stuffing DNA, we now know these intervening sequences contain all of the instructions that tell the cell whether or not to make a specific gene and how much of each gene to make, almost like a computer program provides the instructions to tell the computer hardware what to do. When we refer to “whole exome sequencing,” it means only the 1 percent of the genome that actually encodes the genes (the exons) is sequenced.

**Genes.** Typically, one gene in the human genome includes the blueprint or sequence of letters that provide the instructions to make one particular protein in a cell. Each protein works like a tiny machine within the factory-like environment of a cell to carry out specific tasks that contribute to the survival and function of that cell. The human genome has about 20,000 different genes that can encode at least that many proteins. Different types of cells may “express” or make the proteins from only a subset of those 20,000 genes at any one time, and since there are estimated to be 200 different types of cells in the human body, the subset of proteins expressed by a cell determines whether that cell becomes a skin cell, blood cell, nerve cell or other cell type. When we refer to “single-gene sequencing,” it means the sequence of only one gene is determined. Sometimes, a number of single genes that may all be related to the same disease (like common variable immunodeficiency [CVID]) may be sequenced at the same time as a “panel.”

**Genetic Testing Options Available to Physicians and Patients**

As previously mentioned, there are now a number of different approaches by which patients and providers can have genetic testing performed, including single-gene sequencing, sequencing of a panel of immunodeficiency-related genes, whole exome sequencing and whole genome sequencing. As the costs of sequencing technologies have decreased, these have become increasingly affordable, now ranging from a few hundred dollars to a few thousand dollars, depending on the approach used. The decision of which approach to use depends on each patient’s symptoms and laboratory abnormalities and should be made in consultation with an immunologist, clinical geneticist or genetic counselor. Direct-to-consumer genetic testing options like those currently available through 23andMe, Ancestry.com and others are typically not helpful in identifying the cause of immune-related diseases, simply because the genes that cause these diseases are not included among those for which these services test.

Insurance coverage for genetic testing varies tremendously among carriers. There continue to be some insurance carriers that will not pay for any genetic testing, requiring patients to pay out of pocket. There are others that will pay for one type of genetic testing but not others (i.e., they will pay for a gene panel but not whole exome sequencing), and still others such as Cigna and Aetna that have developed and published criteria for obtaining coverage for whole exome sequencing so patients can determine whether they would be able to obtain coverage.
The likelihood of finding a genetic explanation for a disease depends on how well-defined the clinical picture is. For instance, when symptoms and laboratory testing strongly suggest a classical immune deficiency like X-linked agammaglobulinemia or Wiskott-Aldrich syndrome, the likelihood of finding a mutation in the causative gene is very high. However, in less well-defined diseases like CVID, the likelihood of finding a genetic cause is much lower, recently reported to be 20 percent to 30 percent in those patients with CVID who also have autoimmunity or inflammatory disease.

Benefits of Genetic Testing

There are several potential benefits that arise from identifying the specific genetic cause of a disease:

Making a definitive diagnosis. Many patients have expressed frustration to their providers that they don’t really know for sure what they have. They know they get sick frequently with infections or they have a variety of autoimmune or inflammatory disorders, but putting a specific diagnostic name to their disorder is difficult. As a result, it may be labeled as “CVID,” “combined immune deficiency” or “multisystem autoimmune disorder.” Unfortunately, these generic labels make it difficult to provide specific or useful information about prognosis of the disorder, risk for other family members such as children developing the disorder, or even the optimal course of treatment. Identifying a specific genetic disorder can provide a sense of control. After informing patients that we have identified the genetic cause of their disorder, many have expressed some version of the following sentiment: “I’m not particularly happy to hear that I have a genetic disease, but at least I know what I have and that will help me know how to move forward!”

Family planning. Many patients want to know what the risk level is for other family members to have the same disorder or what the risk is for passing the disorder on to their children. Without knowing the genetic cause of the disorder, the risks that are quoted are usually just a guess. Identification of a gene mutation makes it possible to test other family members who might have similar symptoms, and it allows providers and genetic counselors to give patients an estimate of the specific risk of passing the disease to their children. In addition, knowing the genetic cause of disease makes prenatal testing of a developing fetus possible so families can make informed decisions and providers can plan ahead for the care of the child if he or she has the same disorder. It also allows parents the option of taking advantage of modern reproductive technologies such as in vitro fertilization with preimplantation genetic diagnosis so they may be able to selectively implant only those embryos that lack the mutation.

Insurance justification. It is often much more straightforward to justify to an insurance company why it needs to pay for a particular diagnostic test, procedure or treatment if a patient is known to have a specific genetic disorder.

Treatment planning. Identifying a specific genetic disorder often helps to facilitate or guide treatment decisions in at least three ways.

First, a growing number of U.S. Food and Drug Administration-approved medications, developed to treat various conditions, can target specific proteins or signaling pathways in the cell. And, there are some genetic immunodeficiencies or autoimmune disorders caused by mutations in some of the proteins that are targeted by these medications. So, these medicines can be particularly effective in controlling the symptoms of that genetic disease — almost as if a designer drug had been developed for that specific disorder. Often, that particular medication would not have been considered for treating the disease without knowledge of the gene mutation.

Second, identifying a gene mutation may also facilitate bone marrow transplant in cases that it may be indicated. In the absence of knowing the genetic cause of a patient’s disorder, there is often a delay in treating a patient with a bone marrow transplant, even if it may be indicated, because without knowing what the specific disease is, it is difficult to know whether it will respond to this aggressive treatment option. As a result, transplant becomes a last-ditch option. It also makes bone marrow transplanters hesitant to use siblings as bone marrow donors since they don’t know if the sibling may have the same disorder but may not yet be manifesting symptoms. Knowing the gene mutation allows providers to recommend transplant earlier in the course of disease before patients become more ill and develop more problems. It also allows transplanters to test siblings to determine if they can be safely used as bone marrow donors.

Third, knowing the genetic cause of disease is absolutely essential to determine whether a patient may be eligible for newer therapies such as gene therapy or gene editing in which knowing which gene is mutated is essential before attempting to replace or repair it.
Important Safety Information

WARNING: Thrombosis (blood clots) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

If you are at high risk of blood clots, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor for signs of clotting events and hyperviscosity. Always drink sufficient fluids before infusing Hizentra.

See your doctor for a full explanation, and the full prescribing information for complete boxed warning.

Hizentra is a prescription medicine used to treat:

- Primary immune deficiency (PI) in patients 2 years and older
- Chronic inflammatory demyelinating polyneuropathy (CIDP) in adults

Treatment with Hizentra might not be possible if your doctor determines you have hyperprolinemia (too much proline in the blood), or are IgA-deficient with antibodies to IgA and a history of hypersensitivity. Tell your doctor if you have previously had a severe allergic reaction (including anaphylaxis) to the administration of human immune globulin. Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

Infuse Hizentra under your skin only; do not inject into a blood vessel. Self-administer Hizentra only after having been taught to do so by your doctor or other healthcare professional, and having received dosing instructions for treating your condition.

*Ig=immunoglobulin
Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:

- Reduced urination, sudden weight gain, or swelling in your legs (possible signs of a kidney problem).
- Pain and/or swelling or discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).
- Bad headache with nausea; vomiting; stiff neck; fever; and sensitivity to light (possible signs of meningitis).
- Brown or red urine; rapid heart rate; yellowing of the skin or eyes; chest pains or breathing trouble; fever over 100°F (possible symptoms of other conditions that require prompt treatment).

Hizentra is made from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common side effects in the clinical trials for Hizentra include redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible. Tell your doctor about any side effect that bothers you or does not go away.

Before receiving any vaccine, tell immunizing physician if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Please see brief summary of full prescribing information for Hizentra on adjacent page. For full prescribing information, including boxed warning and patient product information, please visit Hizentra.com.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
**HIZENTRA®, Immune Globulin Subcutaneous (Human), 20% Liquid**
Initial U.S. Approval: 2010

**BRIEF SUMMARY OF PRESCRIBING INFORMATION**

These highlights do not include all the information needed to use HIZENTRA safely and effectively. See full prescribing information for HIZENTRA.

**WARNING: THROMBOSIS**

See full prescribing information for complete boxed warning.

- Thrombosis may occur with immune globulin products, including HIZENTRA. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.
- For patients at risk of thrombosis, administer HIZENTRA at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

**INDICATIONS AND USAGE**

HIZENTRA is indicated for:
- Treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years and older.
- Maintenance therapy in adults with chronic inflammatory demyelinating polyneuropathy (CIDP) to prevent relapse of neuromuscular disability and impairment.

**CONTRAINDICATIONS**

- Anaphylactic or severe systemic reaction to human immune globulin or components of HIZENTRA, such as polysorbate 80
- Hyperprolinemia (type I or II) (HIZENTRA contains the stabilizer L-proline)
- IgA-deficient patients with antibodies against IgA and a history of hypersensitivity

**WARNINGS AND PRECAUTIONS**

- IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions.
- Thrombosis may occur following treatment with immune globulin products, including HIZENTRA.
- Aseptic meningitis syndrome has been reported with IGIV or IGSC, including HIZENTRA treatment.
- Monitor renal function, including blood urea nitrogen, serum creatinine, and urine output in patients at risk of acute renal failure.
- Monitor for clinical signs and symptoms of hemolysis.
- Monitor for pulmonary adverse reactions (transfusion-related acute lung injury [TRALI]).
- HIZENTRA is made from human plasma and may contain infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

**ADVERSE REACTIONS**

The most common adverse reactions observed in ≥5% of study subjects were local infusion site reactions, headache, diarrhea, fatigue, back pain, nausea, pain in extremity, cough, upper respiratory tract infection, rash, pruritus, vomiting, abdominal pain (upper), migraine, arthralgia, pain, fall and nasopharyngitis.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

**DRUG INTERACTIONS**

The passive transfer of antibodies may interfere with the response to live virus vaccines, and lead to misinterpretation of the results of serological testing.

Based on March 2018 revision
**Risks of Genetic Testing**

One of the most frequent concerns expressed by patients regarding genetic testing is whether it will impact their ability to obtain or keep insurance or whether their employer may discriminate against them if a gene mutation is identified. Fortunately, in the United States, the Genetic Information Nondiscrimination Act (GINA) was signed into law in 2008. This law makes it illegal to discriminate against patients with a genetic disease for employment, healthcare and health insurance. GINA does, however, have limitations. It doesn’t apply to employers that have fewer than 15 employees, does not protect against discrimination in other forms of insurance such as life, disability or long-term care insurance, and does not cover individuals serving in the military or those who receive benefits from the Veterans Administration or Indian Health Service. That said, the increasing use of genetic testing in all aspects of medicine and the acknowledgement of the value it provides make it less likely genetic discrimination would be tolerated.

The other concern raised by patients, in light of recent reports of “cold” crime cases being solved by DNA evidence available in public databases, is whether genetic testing could subject them or a family member to be convicted of a crime. In each of these cases, the link between the crime and the perpetrator was made because genetic information was accessed on publicly available websites. Genetic testing performed on a clinical basis is never made available on publicly accessible websites without the patient’s consent, so this information should not be available in a manner that could be linked to an individual or his or her family members.

**Other Recommendations**

It is strongly recommended that if patients have genetic testing performed, they should obtain a copy of that testing for their own records so they have it readily available in case they need to seek care in an urgent care setting or emergency room or if they transfer care to a new provider. In the case of exome and genome sequencing, patients should try to obtain a copy of the actual sequencing data on a hard drive or memory stick for themselves. One reason for this is that because of the massive amount of data included in an exome or genome sequence, it is possible to miss a causative mutation buried within the data. Having the actual data files available would allow that to be reanalyzed over time with new computer algorithms that may be able to identify the causative mutation. In addition, it is likely patients will encounter other non-immune medical issues as they age, and there may be genetic predispositions for those disorders that can be gleaned from that data and that may be helpful in choosing future therapies, etc.

**Consultation Is Advised**

Genetic testing is becoming increasingly accessible to patients with immune disorders, and the growing number of identified gene defects associated with immunodeficiency or autoimmunity has made it increasingly likely that a genetic cause for a particular disease can be identified. While there are clear risks and benefits to genetic testing, consultation with a trusted immunologist, geneticist or genetic counselor can help to determine whether it is appropriate in a patient’s case and which method would be most likely to yield a helpful result.

**TROY R. TORGERSON**, MD, PhD, is an associate professor of pediatrics and immunology/rheumatology, director of the Immunology Diagnostic Lab and co-director of the Non-Malignant Transplant Program at the University of Washington and Seattle Children’s Hospital in Seattle, Wash.
Sleep and the Immune System Link

Because research shows lack of sleep further impairs the immune system, making individuals more prone to infection, PI patients should consider sleep an important part of their daily health regimen.

By Jim Trageser

BENJAMIN FRANKLIN is credited with saying: “Early to bed and early to rise makes a man healthy, wealthy and wise.” The record is unclear if Franklin actually ever wrote or said that quote widely attributed to him, but it is reflective of the long-held cultural belief that a good night’s sleep is critical to the next day’s success. Generations of children stretching back to time immemorial have been told they need to get to bed if they want to do well at school the next day.

As it turns out, science backs up the need for a good night’s sleep. Whether a person hits the sack early or late, getting that full period of rest is necessary to maintain good health. As diurnal animals, human beings are designed to sleep at night. And sleep — which is near-universal across vertebrates — serves important biological functions. It’s a built-in maintenance period for bodies, a time for an internal janitorial service to do regular cleaning and minor repairs to keep systems in good working order. And the immune system is particularly vulnerable to disruptions of sleep patterns. When people don’t get enough sleep, either from an overly busy life or due to medical problems causing insomnia, they are more prone to infection.

What Happens When People Sleep

When people sleep, their bodies function differently than when they’re awake. Breathing and heart rate slow, temperature drops and voluntary muscles are temporarily turned off (preventing people from acting out their dreams). Different hormones and different amounts of hormones are released to help regulate everything from appetites to the ability to fight off infections.

Researchers now believe normal human sleep can be divided into a series of four alternating stages:

• Stage 1 non-REM sleep: This is the period when people first fall asleep. Brain waves begin to change pattern, and breathing begins to slow.
• Stage 2 non-REM sleep: In this period, eye movement stops, brain activity lessens and heart rate and breathing slow further. About half of each night is spent in successive cycles of this stage.
• Stage 3 non-REM sleep: This is the deepest
sleep, when it is hardest to wake up. Researchers also believe successful completion of this stage is what allows people to feel refreshed the next day.

- REM sleep: The acronym for “rapid eye movement,” the first REM stage usually occurs about 90 minutes after falling asleep. The eyes are moving, brain waves are active and heart rate and breathing are close to what they were when awake. Most dreams occur during this stage when the brain temporarily paralyzes the arm and leg muscles.

Stages 2 and 3 and REM sleep will alternate throughout an eight-hour sleep period, averaging three to five cycles per night. Sleep is controlled by a complex network involving different parts of the brain. The hypothalamus communicates with the eyes, and it helps regulate the circadian cycle so most people sleep during the night. The pineal gland starts pumping out melatonin (which helps people stay asleep) once the hypothalamus tells it that it’s dark and time for sleep.

What Happens When People Are Sleep-Deprived

Being sleep-deprived does not mean no sleep at all; it simply means the body did not completely cycle through a normal sleep pattern, meaning it got less than the six to nine hours most people need. (Children and teens need nine to 10 hours, most adults need seven to eight hours, and older adults may need as little as six hours.) Experts believe about 20 percent of American adults suffer some form of sleep deprivation.

When the body fails to get enough sleep, its normal diurnal functions are interrupted. Too little sleep means the body won’t make enough cytokines — key proteins that help stimulate and regulate the immune system. Normal organ and cell repair also is shortened. During stage 3, heart rate slows and blood pressure drops, giving the heart and blood vessels needed rest. Without that, the cardiovascular system doesn’t get the healing it needs, either.

Short-term immediate symptoms of sleep deprivation generally include fatigue, difficulty concentrating, increased sleepiness, irritability, anxiety and/or restlessness. Even short-term sleep deprivation can have devastating consequences: While the National Highway Traffic Safety Administration attributed 800 deaths to accidents caused by drowsy drivers in 2013, the Centers for Disease Control and Prevention says that number is wildly underreported, and it’s more likely 6,000 fatalities a year are due to drowsy driving.

When people regularly fail to get enough sleep, they have sleep deficiency. Long-term or chronic sleep deprivation can lead to more serious medical problems, including depression, high blood pressure, obesity, stroke and even diabetes.

If people are unable to sleep (as opposed to making lifestyle choices that lead to not enough sleep), they are said to have insomnia. There are numerous causes of insomnia — from chronic pain to asthma, acid reflux to apnea, or an enlarged prostate in men.

How the Immune System Is Affected

As mentioned, part of the normal sleep cycle is an increased production of chemicals known as cytokines. Cytokines are small proteins that circulate throughout the body.
They cannot enter the body’s cells, but they can interact with other molecules on the surface of cells to serve as a signal from the body’s immune system to individual cells.

When normal sleep patterns are short-circuited, the cells that produce cytokines — T and B lymphocytes, macrophages and mast cells, among others — don’t have the opportunity to create as many as they would during normal sleep. Having too few cytokines interferes with the ability of the body to effectively react to the presence of foreign microorganisms, making the body more susceptible to viral, bacterial and fungal infections. One study found a correlation between immunity against the flu and sleep deprivation, with sleep-deprived mice losing previously developed immunity.8

A 2012 study showed undifferentiated T cells also are produced primarily during sleep, and regular sleep helped ensure they were properly deployed to the lymph nodes.9 A protein known as integrin that assists T cells in attaching themselves to invading microorganisms is also impacted by a lack of sleep, which is another way the immune system can be compromised by sleep deprivation.10

Another study conducted in 2016 followed 11 pairs of identical twins who had different sleep patterns and found the twin who didn’t get as much sleep had a measurably weaker immune system.11 Interestingly, it is now believed narcolepsy, which causes patients to suffer from excessive daytime sleepiness, often falling asleep in public situations, is caused by a faulty immune system gene, resulting in the production of too little hypocretin.12

The Importance of Sleep for Primary Immunodeficiency Disease Patients

Because lack of sleep further compromises the immune system, patients with a primary immunodeficiency (PI) should include sleep as an important, indeed critical, component of their daily health regimen. Having enough sleep, but also the same sleep pattern on a daily basis, can help maximize their body’s ability to fight infection.13

Getting enough sleep may also put PI patients at lower risk of developing autoimmune disorders. In fact, some researchers believe long-term disruption of normal sleep cycles (for many weeks or months) may actually trigger autoimmune conditions such as fibromyalgia and chronic fatigue syndrome because of how sleep deprivation impairs immunity and affects the musculoskeletal system.14 One study of almost 85,000 adult patients diagnosed with non-apnea sleep disorders showed those patients were at higher risk for developing autoimmune disorders.15

On the other side of the spectrum, fatigue and nonrestful sleep are common and often debilitating components of autoimmune disease. In fact, sleeping problems are considered reliable warning signs for a variety of autoimmune conditions.14

Doctors recommend avoiding alcohol or caffeine in the evening, not snacking before bedtime, and not taking long naps during the day.16 And, given that depression is a major cause of insomnia, as well as a result of it, PI patients should be sure they are working with their physician to keep an eye out for either depression or sleep deficiency.

Addressing Sleep Deprivation

The only treatment for sleep deprivation is more sleep. Short-term coping mechanisms are just that; they can assist with staying awake and functioning in the aftermath of sleep deprivation, but they won’t restore balance or full health. Only regular, full nights of sleep can do that.

For those who suffer from insomnia, treatment for the underlying cause will be necessary to restore regular sleep patterns. But, this needs to be discussed with a physician, because symptoms of sleep deprivation can also have many other causes, so a doctor may not immediately suspect sleep deprivation.5 In fact, most sleep deprivation goes undiagnosed and, thus, untreated.

Patients who are considering talking with their doctor should consider keeping a sleep log for a few weeks before the appointment. The log should include what time they went to bed, when they think they fell asleep, and how long they slept. It should also note how many times they woke up and how long it took them to fall back asleep. If vivid dreams or nightmares awoke them, those should be noted, too. In addition, it helps to track caffeine and alcohol consumption, naps and medications. The National Sleep Foundation has a sleep...
Looking Ahead

A good night’s sleep is not a luxury; it is as important to overall health as a good diet and regular physical activity, and for those with a PI, it is even more important. While various cures for insomnia are being studied, there are already many effective treatments available.

Simply being aware of sleep deprivation is a big part of the solution. Much sleep deprivation isn’t due to medically caused insomnia, it’s simply a lack of awareness and a lack of commitment to getting needed sleep.

JIM TRAGESER is a freelance journalist in the San Diego area.

References

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Harnessing the Power of the Mind Through Images

By Meredith Whitmore

Guided imagery can provide physical and/or emotional relief, but it takes practice and professional guidance is often needed.

LET’S EXAMINE through a simple exercise a superpower that most people have without realizing it. First, imagine a lemon. See its color. Feel its rind with your fingertip. Visualize yourself holding a cold lemon wedge in your hand. Feel its moisture. Run your finger along the pulp. Smell its fragrance. Now, sink your teeth into it and taste the juice squirt into your mouth. Are you puckering? Salivating? Cringing? If so, your response is common. And, that powerful mind-body connection is your latent superpower. In other words, your mind has the ability to forcibly, tangibly change your body’s physiological functions through only your imagination.

Physical reactions such as feeling nauseated when imagining something disgusting or feeling anxious when reading a chilling story or action novel also demonstrate the mind’s ability to physically alter the bodily state through mental images. Minds and bodies, in a very sophisticated capacity, work together to respond corporeally to what is only envisioned.

“Words and images are magic to us, and they change our brains,” says clinical psychologist Joseph Rhinewine, PhD, director of Portland Mindfulness Therapy, in Portland, Ore. “Just picturing a lemon — or a food we crave or have a special memory of — causes our bodies to make an actual glandular change, even though there’s no lemon. The parasympathetic nervous system kicks in, activates the salivary glands, and voilà. There’s saliva in your mouth, and you taste a lemon. That’s magic.”
The lemon illustration is an example of guided imagery, a therapeutic technique in which individuals visualize and focus on mental images to evoke physical feelings such as peace, joy or even pain relief. When the visual cortex of the brain is activated through one’s imagination, even without actual visual stimuli, it can greatly influence a person’s emotions and cause other very strong physiological responses in the body. “We can’t even understand each other, we can’t even have language, we can’t even have truly human communication without this function of ‘thought entanglement,’ which means we confuse thoughts and images for the things themselves,” explains Dr. Rhinewine. “This entanglement, accessed through guided imagery, can help a person to elicit positive changes in their lives that can heal, whether their underlying problem is physical or mental.1

Dr. Rhinewine further clarifies how images (words, thoughts, visuals) can be used in healing: “This therapy can do one of two things. Either we try to weaken the influence and undermine the magic of language on behavior (for example, the thought ‘I’m fat and stupid and no one will love me’), or we can augment and ‘juice up’ the entanglement in order to strengthen a concept, and that’s what guided imagery is all about.”

Studies show actual physiological changes can be seen on functional MRI (fMRI) images that reveal the brain’s altered state as people practice guided meditation.2,3,4 There is visible physical activity in the brain when people perform such exercises. In addition, various studies indicate this technique, though it often requires patience and practice, can even reduce nausea and pain in cancer patients, reduce stress, manage grief, help with addiction, and help a person to better cope with various other mental health issues.2,3,4 “If we can access a peaceful place in our minds, our occipital and temporal lobes respond as if we are actually in that peaceful place,” says Jessica Huffman, MA, a counseling professor in Salem, Ore. We can see this on an fMRI. The brain is absolutely working with those mental images. It truly is a physical shift, and if we can get there, we can create neural pathways there so the brain does it without as much effort.”

Guided imagery can also help people have more restful and restorative sleep. This is because, as Huffman explains, “You are putting your body in a state where you are imagining the way a pleasant place smells. You’re imagining the sounds. You’re feeling the breeze on your face. You’re picturing a meadow or lake or something else that’s very peaceful to you. You are actually putting your mind there. Then, your body responds as if it is there.” And a body that feels it is at peace in a peaceful environment will respond in kind during sleep.

But, long before fMRIs and other modern technologies, the ancients knew of our amazing mind-body connection. Aristotle and Hippocrates, among others, understood the power of mental images and their ability to affect both body and soul, and they encouraged the practice. Today, Aristotle’s and Hippocrates’ foundational beliefs are being studied and expanded. As neuroplasticity (the brain’s ability to reorganize itself by forming new neural connections and pathways) is better understood, so is guided meditation and imagery. And, fMRI has proven guided imagery’s efficacy as it is used to help people heal from a variety of ailments, including managing grief, reducing fear and stress, and managing headaches, among many others.1
Modern History of Guided Imagery

In the 1970s, David E. Bresler, PhD, LAc, a health psychologist and acupuncturist, and Martin L. Rossman, MD, a medical doctor, were among the first to begin to study and implement guided imagery with their patients. Dr. Rossman’s seminal book, *Guided Imagery for Self-Healing*, is still in print and offers wisdom for those who would like to learn more and possibly begin simple exercises in guided imagery on their own. These men set the precedent for today’s practices, which include more and more hospitals implementing guided imagery’s potent ability to help heal.

As a caveat, however, guided imagery should never be taken as a cure-all or a casual approach to therapy. Nor does it work for everyone, depending on their capacities and needs. Guided imagery can even have negative consequences with certain conditions, since false memories and other complications may come into play. Overall, however, even when the latter occurs, guided imagery under the right circumstances can be helpful, especially when used under the expertise of a trained mental health provider.

How Does It Work?

With regard to the nuts and bolts of “how-tos,” Huffman, who has helped many clients utilize guided imagery to manage chronic pain, offers helpful insight. First, she warns those who might find this type of therapy intriguing that it can take time to learn and feel comfortable with it. “It’s important not to be too quick about it because people need a basic understanding of things such as diaphragmatic breathing, for example, and how to get their body to a relaxed state before they do any kind of imagery practice,” she says. “Otherwise, the imagery can be very triggering and can actually induce pain. You have to start at the basic level. Guided imagery, or any kind of imagery, really, is the next level, so to speak, in mindfulness practices for pain.”

In terms of procedure, Huffman says, “The therapist provides the generic script, and then the client gets to craft it together in order to make it personal.” In this way, a client can feel safe and benefit from a script they have personally created to fit their needs. Huffman believes, too, that it’s important to realize guided imagery takes time to learn. It can take a few weeks to build foundational diaphragmatic breathing practices (for relaxation), and then it can take some time to explore the emotional connection to the pain, for example, if pain is what a client is working toward reducing.

Huffman says she and other therapists often craft a generic guided imagery script first. In this way, the client can feel safe and start the preliminary work. Then, the client gradually “crafts his or her own script to make it personally tailored to their own needs.” For example, if people have seasonal allergies, they shouldn’t imagine themselves in a field of flowers or grass to find rest. They need to find their own mental “place” and make it their own for comfort and healing tailored to their situation. They also should not allow any therapist to dictate what the script should be.

Huffman offers a clear illustration of her own guided imagery practice: “One script I have for myself is a cabin in the woods. I have a hammock and I imagine going there. I feel the breeze and smell the campfire smoke. I’ll walk through that script, and there are many different ways I can get to the cabin. Sometimes, I’ll drive my car there. Sometimes, I’ll hike up a mountain. Sometimes, I’ll raft down a river. The scripts can build and change the more a person continues to do guided imagery.” That is, if a script begins to feel stale, a person can always change something to have a new experience and keep the experience fresh, since too much repetition can feel monotonous. “The more a person does this, the easier it is for the brain to ‘go’ to that place of peace in their mind,” Huffman adds. “Because I have been doing guided meditation for so long, it takes me just a minute to find it. A neural pathway has been created, and a person can take that neural shortcut to find relief. The end game for this technique is to be able to have such a place that you can access almost immediately [when you need relief].”
“The general goal of guided imagery is to reduce suffering,” explains Huffman, “not necessarily pain, but suffering, which could mean easing a person’s experience of the pain, their perception of the pain, reducing the interference of the pain in their life activities, developing a higher tolerance to the pain.” This pain can be physical or mental. “The question we ask is, how can we widen the window of how we tolerate the amount of pain we can take before our physical or emotional breaking point?” adds Huffman. “What is making that window narrower than we’d like, and how can we expand that? Guided imagery can help expand that window.”

Doing It Yourself

Bearing in mind the aforementioned caveats, of course, simple guided imagery can be practiced without the help of a therapist in some cases. There are phone apps, books and websites such as www.healthjourneys.com, among other resources, to assist the process. This technique can be accessed whenever someone needs it during the day. If people feel stressed and want to better handle the emotional dysregulation, they can find an outlet through guided imagery, which will help their mind and body to find a sense of calm within the storm. It is a matter of checking in with their body, so to speak, and going to their proverbial “happy place” that can help their body to regulate and calm down. But, as mentioned earlier, it takes practice, and it is helpful to seek professional guidance.

MEREDITH WHITMORE is an English professor and freelance journalist in the Northwest.

References
HEALTH INSURANCE IS a safety net to provide people with financial protection in the event of sickness or injury. And, while no one plans on becoming ill, it is a possibility. Responsible people understand and prepare for that prospect by purchasing health insurance. But, how do people protect themselves and their families if the illness is chronic and will require treatment for an extended period or for the rest of their lives? The answer may be chronic illness insurance.

Chronic illness is defined by the Centers for Disease Control and Prevention (CDC) as a condition that lasts one year or longer and requires ongoing medical attention or limits activities of daily living or both. The cost of treating a chronic illness can be devastating, particularly if patients require specialized treatment, equipment or help with daily living activities not covered by health insurance.

Indeed, medical bills are the leading cause of bankruptcy, so the need for financial protection is greater today than ever before. The number of people dealing with chronic illness and its related expenses is larger than most realize. According to statistics, 133 million Americans have at least one chronic illness. Further, it is estimated by 2025, that number will grow to 164 million people or nearly half the population. These numbers are sobering considering 80 percent of the population older than 55 years has less money saved for retirement than they will likely need to cover their medical expenses alone.

What Is a Chronic Illness Rider?

Often, people assume health insurance will cover their medical needs if they become ill. Unfortunately, that isn’t always the case. When seriously chronically ill, people may not be able to pay their health insurance premiums, or they may need help performing activities of daily living not covered by a regular health insurance policy such as bathing, preparing food or dressing.

A chronic illness rider is an addition to a standard life insurance (or mortgage protection life insurance) policy that pays for medical and nonmedical care that health insurance does not cover if diagnosed with a qualifying illness. It is a relatively new concept similar to a long-term care policy that has been available for years to address people’s inability to perform daily activities. Funds are paid in one lump sum directly to beneficiaries, and they can be used in whatever manner is needed such as for medical bills and/or assisted care, or for modifying a home to make it more accessible. In addition, these funds are not intended to be taxed, although individuals should always consult first with a tax advisor.

A chronic illness rider is often lumped with critical illness and terminal illness riders. The rider allows individuals to use their life insurance benefit while still alive as an accelerated death benefit. The amount of funds available depends on the terms of the policy. Some policies will allow access to all of

Benefitting from Chronic Illness Insurance

For the rising number of Americans diagnosed each year with a chronic illness, additional insurance that pays for medical and nonmedical costs may be the answer to ensuring their needs are met.

By Abbie Cornett
the death benefit in advance. And, depending on the policy, the rider may be added at no additional cost and will cover care up to the amount specified.

The advantage to buying a rider rather than a separate policy is the benefit does not have to be accessed if it is not needed. When it is not accessed, it is still available to be paid to beneficiaries upon the policyholder’s death. For instance, if a person takes out a life insurance (or mortgage protection) policy for $50,000 with a chronic illness rider of $10,000, in the event of a chronic illness, that person would receive the $10,000 in a one-time payment. The $10,000 is part of the insurance money (death benefit) that would have gone to beneficiaries if not used. But, if it is used, beneficiaries will receive only $40,000. The rider is not additional money; it is part of the insurance money from that life insurance policy that is available while still alive (also known as a “living benefit”).

### Accessing Chronic Illness Rider Benefits

A chronic illness rider will pay a benefit when a licensed healthcare professional certifies the policyholder has a qualifying condition that limits his or her ability to perform two of six activities of daily living (ADLs) or has a permanent severe cognitive impairment requiring substantial supervision (see 6 Activities of Daily Living).

When deciding whether to use the benefit, it is important to assess the impact to the life insurance policy. If the accelerated benefit is used, it will lower the amount of life insurance available to beneficiaries after the policyholder dies. Therefore, it is important to look at other finances that could be of assistance, including other insurance coverage and Medicare and Medicaid benefits.

Many people are unaware that Medicare will provide some support for costs associated with long-term care hospitals, skilled nursing facilities, home health service providers and hospice care providers. Medicare, though, is only a short-term solution for long-term care. Medicaid, on the other hand, can help with a long-term care solution if the individual meets the strict qualifying income. Medicaid’s Home- and Community-Based Services waiver program is designed to pay for many services that would be impossible for seniors to afford on their own such as homemaking, personal care and even adult day healthcare services when needed.

### Long-Term Care vs. a Chronic Illness Rider

Rather than a chronic illness rider, a long-term care rider may be considered instead. The differences between a long-term care and a chronic illness rider are subtle but significant. Both are designed to help with expenses related to a long-term condition. However, a long-term care rider offers more flexibility.

A chronic illness rider requires an individual to have a qualifying condition that limits his or her ability to perform a minimum of two of the six listed ADLs, or a permanent cognitive impairment that limits the person’s ability to perform instrumental activities of daily living (IADLs) with no potential for recovery (see Instrumental Activities of Daily Living). On the other hand, a long-term care rider may also be paid if a person has severe cognitive decline that limits his or her ability to perform IADLs regardless of the ability to perform ADLs. Further, unlike a chronic illness rider, a long-term care rider can provide benefits for conditions that are both temporary and permanent. For example, if a person had to have surgery that required a stay in a rehabilitation center, a long-term care rider would provide benefits while there, and then would stop benefits until they are needed again. A chronic illness rider would not cover the stay since the condition would not be considered permanent.

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**6 ACTIVITIES OF DAILY LIVING**

1. **Bathing**
   - getting into and out of the bathtub, washing, brushing teeth, shaving or performing other grooming activities

2. **Dressing**
   - pulling clothes on, fastening buttons or closing zippers

3. **Eating**
   - managing the silverware to eat independently

4. **Transferring**
   - walking or otherwise transferring from a bed to a wheelchair and back

5. **Toileting**
   - getting on and off the toilet without help

6. **Continence**
   - controlling bladder and bowel functions
But, there are also two downsides to the long-term care rider. First, unlike a chronic illness rider, if the benefit goes unused, the money paid for the premium is lost. Second, whereas a chronic illness rider can be used for anything after the payment is made, a long-term care rider may require evidence of actual paid expenses and may be paid as reimbursement.

### Instrumental Activities of Daily Living
- Managing finances
- Handling transportation (public transit or personal driving)
- Shopping
- Preparing meals
- Using the telephone
- Managing medications
- Performing housework and basic home maintenance

### Top 10 Best Companies Offering Long-Term Care Policies and Chronic Illness Riders

The following table of companies is Asurea’s current list of insurers that provide either long-term care policies or chronic illness riders. There is no one best company. The right company is based on specific goals and objectives.

<table>
<thead>
<tr>
<th>Company</th>
<th>Type of Rider</th>
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<tbody>
<tr>
<td>AIG</td>
<td>Chronic Illness</td>
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<tr>
<td>AXA Equitable</td>
<td>Long-Term Care</td>
</tr>
<tr>
<td>Lincoln National</td>
<td>Chronic Illness</td>
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<tr>
<td>Life Insurance of the Southwest</td>
<td>Chronic Illness</td>
</tr>
<tr>
<td>MassMutual</td>
<td>Long-Term Care</td>
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<tr>
<td>Minnesota Life</td>
<td>Long-Term Care</td>
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<tr>
<td>North American</td>
<td>Chronic Illness</td>
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<tr>
<td>Pacific Life</td>
<td>Chronic Illness</td>
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<tr>
<td>Penn Mutual</td>
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<td>Principal</td>
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<td>Prudential</td>
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<tr>
<td>State Life</td>
<td>Long-Term Care</td>
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<tr>
<td>Voya</td>
<td>Chronic Illness</td>
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### Purchasing a Policy After Diagnosis

Ideally, people have insurance before they need it since after diagnosis, it is much more difficult to get. However, even if life insurance is not purchased prior to diagnosis of a chronic illness, it is not necessarily too late. It may depend on the condition or the type of life insurance. Some policies will not require a medical exam or will offer guaranteed coverage. Existing life insurance policyholders should check to see if it includes accelerated (living) benefits. Also, prior to purchasing any policy, it is wise to check the rules on preexisting conditions, waiting periods, excluded benefits and any age restrictions that may apply.

### Ensuring Financial Well-Being

With the number of people in the U.S. with a chronic illness rising to almost half the population in just half a decade, chronic illness insurance may be the only way to ensure medical needs are met and family members are financially protected. However, the decision to purchase chronic illness insurance depends on many factors. Besides affecting physical health, the cost of a chronic illness can impact both individual and family financial well-being. If resources are available to guarantee a family can manage the disease and its related costs, then purchasing chronic illness insurance is probably not necessary. But, for most, those resources aren’t sufficient. Fortunately, chronic illness insurance is now an option. And, even when not purchased prior to a diagnosis, a policy is still possible to obtain.

### References


### ABBIE CORNETT is the patient advocate for IG Living magazine.
NERVE PAIN CAN cause burning, stabbing, aching, shooting pain and/or tingling/prickling sensations. Nerves act as the transmitters (or highways) for pain signals back to the central nervous system, and they play a role in all peripheral pain, even when the pain doesn’t originate from the nerve itself.

Neuropathy is a disease or dysfunction of the nerves. Depending on whether sensory, motor and/or autonomic nerves are involved, peripheral neuropathy may manifest itself as pain, numbness, weakness, altered temperature regulation and/or other symptoms in the upper and lower extremities on either or both sides of the body. Those who suffer from peripheral neuropathy often experience a decline in independence that can result in feelings of dejection and forcibly cause them to give up activities they once found enjoyable. And, while peripheral neuropathy can be prevented in some instances, sometimes the only option is to properly care for the disease and prevent it from getting worse.

Preventing Neuropathy

Until epidemiologists or geneticists can definitively identify the cause and eradicate some of the most devastating diseases related to neuropathy, care rather than prevention is the best solution. That being said, preventive practices can be taken to reduce the duration, severity and/or functional impact of neuropathies.

For those living with a primary immunodeficiency, neuropathies are typically a secondary symptom and not directly related to the underlying condition. Therefore, direct prevention is possible, and oftentimes the neuropathy may be reversed if identified and treated before permanent damage occurs. As is true for reducing the risks of most medical problems, safe and healthy living is key: regular exercise, not smoking or being overexposed to environmental toxins, and consuming a nutritious diet that avoids high salt, alcohol, saturated fat, sugar and other inflammatory foods.

Obesity, high blood pressure and diabetes are often closely related conditions that all increase the risk of neuropathy, whether they occur together or in isolation. If a patient has diabetes, it is particularly important that blood glucose levels be controlled. However, artificial sweeteners should be used in moderation due to their potential for increasing the sensitivity of nerves and making symptoms of neuropathy worse.

In addition to nutritional risk factors, both traumatic injuries and more insidious compression or repetitive high-impact injuries may lead to neuropathy. Maintaining neuromuscular flexibility, but not overstretching, will help to avoid neural compression/entrapment such as occurs with carpal tunnel. Repetitive stress neuropathies are particularly common in the feet. If persons are obese or otherwise at increased risk of developing this type of neuropathy, it’s best they participate in reduced weight-bearing exercises such as stationary biking or swimming instead of high-impact choices that involve running or jumping.

Regardless of the underlying cause, early detection and care of neuropathy is vital due to the peripheral nerves’ limited ability to regenerate. Patients should disclose all symptoms and concerns early and thoroughly with their doctor who can determine what diagnostic testing may be necessary to make an appropriate referral.

By Matthew D. Hansen, DPT, MPT, BSPTS
Caring for Neuropathy

The main treatment goals for neuropathy are to manage the underlying condition and to relieve its symptoms. Effective care must oftentimes be multifaceted and is presented here by category.

Preventive care against injury. Those suffering from a sensory neuropathy in the hands and/or feet may experience hyposensitivity or complete numbness in one or more extremities. Consequently, it is not unusual for them to be less aware of harmful stimuli in their environment, including obstacles in their pathway when other senses are impaired. For example, someone with impaired proprioception (sense of body position) due to lower extremity neuropathy is even more dependent on their sense of vision for balance, and may be more susceptible to tripping and falling when getting up in the dark to go to the bathroom during the middle of the night. Decreased sensation in the feet also makes people more prone to injury because they may not feel something as seemingly innocent as a pebble in their shoe or the ensuing wound and infection that may develop. Those with an upper extremity neuropathy may not be able to tell their hand is on a hot stove or in scalding water.

The following are several self-care and home safety measures that can help to prevent injury and harm:

• Perform regular foot checks for blisters, cuts, etc.
• Wear soft cotton socks that are not too tight, use shoes with a padded heel, avoid high heels or going barefoot and trim toenails regularly.
• Keep pathways free of obstacles, and utilize night lights.
• Install grab bars in the bathroom, and use bath mats.
• Check water temperature with a thermometer or elbow and not with a hand or foot.

If neuropathy is caused by a nutritional deficit, addressing the deficiency may be enough to resolve symptoms. If neuropathy is caused by use of a specific medication, switching to an alternative drug, as prescribed by a physician, may be the answer. Still, with some causes, neuropathic damage may be permanent.

Exercise and rehabilitation. Many sensory neuropathies have the potential to resolve over time; however, there are steps that can be taken to help reduce pain. In fact, something as seemingly simple as getting up and moving every 20 minutes to 30 minutes can help decrease pain by maintaining blood flow to the nerves and preventing muscle and nerve contractures. An easy walk, yoga or tai chi are good starting activities that can provide physical and mental benefits.

Arranging for an ergonomic and safety assessment of work and living spaces, followed by making recommended changes, may also make a difference. This type of evaluation can be performed by one of several specially trained professionals, including an occupational or physical therapist. Skilled therapy or chiropractic intervention can also help reduce pain via guided exercise, desensitization techniques, manual intervention or use of other therapies. One modality that has been shown to offer relief for some is transcutaneous electronic nerve stimulation (TENS). The theory behind TENS is that painful signals running through the nerves can be disrupted from their pathway to the brain by passing a gentle current through electrodes placed on the skin.

When symptoms interfere with function, a therapist can help to compensate for lost skills by teaching new ones and/or prescribing adaptive equipment. A therapist may also recommend a sling or splint to protect surrounding tissue in the affected area and to help maintain range of motion, or fit and train the patient to use a cane, walker or wheelchair, even for temporary use.

With motor neuropathy, it’s important to protect the body’s joints and muscle structures from unnecessary stress. Strengthening exercises help to maintain affected muscles, but it’s critical they be prescribed by a professional who understands motor neuropathy and the patient’s specific condition. Strengthening and balance exercises also increase safety by fortifying the muscles in nonaffected surrounding areas.

Medical intervention. Neuropathic medications include typical over-the-counter pain medications, including acetaminophen and nonsteroidal anti-inflammatory drugs (e.g., ibuprofen, aspirin and naproxen), as well as drugs primarily developed and used to control other medical conditions. For
example, anti-seizure medications such as pregabalin and gabapentin, along with several antidepressant drug classes, have been shown to help relieve chronic pain. Topical applications of lidocaine or capsaicin cream (which contains the active chemical compound found in chili peppers) also have analgesic qualities. When more conservative measures fail, a physician may decide to perform a nerve block by injecting an anesthetic directly into the nerve. Pain killers that contain opioids (e.g., oxycodone, fentanyl, codeine and morphine) are now usually used only when other treatments are unsuccessful due to their capacity to lead to dependence and addiction.

Other medical treatments for neuropathy include intravenous immune globulin (IVIG) and plasmapheresis (plasma exchange). IVIG is used to infuse the body with additional antibodies when the immune system is low. Plasmapheresis is a blood transfusion that is designed to remove hazardous antibodies from the blood that attack nerve cells leading to neuropathy in individuals with autoimmune disease.

Finally, surgical treatment may be recommended as a last resort or if it can be determined the neuropathy stems from resolvable pressure or compression on the nerve.

Alternative interventions. Although not as much scientific research has been performed for the following treatments as for pharmaceutical intervention, they have all benefited from growing interest and anecdotal support.

• Medical marijuana: A review funded by the Veterans Administration of 13 clinical trials concluded, “Limited evidence suggests that cannabis may alleviate neuropathic pain in some patients, but insufficient evidence exists for other types of chronic pain.” The authors also determined that additional studies on its safety and long-term efficacy were needed.1 With more states legalizing medical marijuana, there is sure to be more research to follow.

• Relaxation techniques: Many techniques have developed over the centuries to help adherents release inner tension and refocus the body and mind. Some of those practices include meditation, self-hypnosis, visualization, biofeedback, progressive muscle relaxation, conscious breathing and/or yoga.

• Natural supplements: At least a dozen different vitamins and herbs have been promoted for their ability to relieve nerve pain. These include vitamins A and B, St. John’s wort, kava kava, ginseng, alpha-lipoic acid, acetyl-L-carnitine, N-acetyl cysteine, curcumin (found in turmeric and ginger), fish oil and some essential oils (e.g., Roman lavender and chamomile). Natural supplements may still have side effects, as well as possible interactions with prescribed medications, so their consideration should be discussed with a physician prior to use.

• Acupuncture, acupressure and reiki: According to Far Eastern tradition, these techniques promote healing by balancing the flow of energy through the body. Though scientific research regarding their effectiveness in the treatment of neuropathy is conflicting, their techniques have been adopted or adapted by Western medicine, often with different theories for their use and effectiveness (e.g., dry needling vs. acupuncture).

Many techniques have developed over the centuries to help adherents release inner tension and refocus the body and mind.

Relief Is Possible

Prevention, when possible, is always the best medicine. However, when it’s not, sufferers of peripheral neuropathy should never give up hope. Instead, by taking time to share their symptoms with their doctor, learn about their condition and systematically and thoroughly attempt different treatment options, patients should eventually find some relief if not resolution from their neuropathy. In the case of chronic and/or progressive conditions, at the very least, patients can learn through skilled assistance how to continue and function at their new normal.

MATTHEW DAVID HANSEN, DPT, MPT, BSPTS, is a practicing physical therapist in Utah and president of an allied healthcare staffing and consulting agency named SOMA Health, LLC. He completed his formal education at the University of Utah, Salt Lake City, and has additional training in exercise and sports science, motor development and neurological and pediatric physical therapy.

Reference

Profile: Kelley and Connor Hodges

By Trudie Mitschang

IN JANUARY 2014, Kelley Hodges read an article in IG Living written by Terry Harville, MD, PhD, outlining how an antibody deficiency is diagnosed. Her interest was piqued because her formerly healthy 17-year-old son, Connor, had been diagnosed with Epstein Barr virus (EBV) and, later, common variable immunodeficiency (CVID). Because the family lived in a small town with limited access to specialty medical care, Kelley hoped Dr. Harville could offer some much-needed advice. Not only was Dr. Harville able to answer her specific questions surrounding Connor’s diagnosis, he also referred her to several nearby specialists with expertise in Connor’s condition. Five years later, Connor is now a college senior and an award-winning NCAA Division 1 swimmer, graduating with honors and successfully managing his own healthcare. We caught up with Kelley and Connor to hear their stories.

Connor Hodges, pictured with his mother Kelley, father Michael and sisters Mikayla and Katy, was diagnosed with CVID after contracting the Epstein Barr virus.

Trudie: Tell us about Connor’s journey to diagnosis.

Kelley: In the summer of Connor’s junior year in high school, he contracted EBV and was sick several times after that. Initially, we didn’t know he had EBV, but after being sick for the third time, we took him to his long-time pediatrician who ordered blood work that showed he had IgG levels below 200. His pediatrician called me on his 17th birthday to tell me he needed to have an X-ray and additional blood work — that day. Since Connor had little history of being sick and had never been hospitalized, I didn’t understand her concern. She scheduled an appointment with an immunologist, but the closest appointment we could get was three months away. Connor didn’t show any signs that something was wrong; he swam four hours a night, never missed school and was earning all As in school. In November, he met with an immunologist who gave him the pneumovax vaccine and, in December, he became ill with a virus. We didn’t treat it because he seemed fine with the exception of having a sore throat. Then, on December 30, he had a tonic-clonic seizure at 6 a.m. We took him to his pediatrician who admitted him to the hospital for testing. On January 1, he was diagnosed with CVID.

IG Living: What led you to reach out to Dr. Harville?

Kelley: After Connor’s diagnosis, I researched everything I could about CVID and its connection to EBV. I found a case study written by Dr. Harville about a young man who was 17 when he contracted EBV, which resulted in CVID. I was encouraged because the patient showed signs of recovery when he was 24. I decided to email Dr. Harville and share our story.

IG Living: How did Dr. Harville’s advice help Connor?

Kelley: I am grateful every day that he decided to answer an email from a mother in Florida who needed help and advice. He pointed me toward experts in our area who conducted research and were very knowledgeable about CVID. We ended up seeing Dr. Harry Schroeder at the University of Alabama (UAB) who evaluated Connor and corrected his immune globulin (IG) therapy dosage.
**IG Living:** What has been the biggest hurdle, and how did you overcome it?

**Kelley:** Initially, the biggest hurdle was finding a doctor. Connor was 17, not really a child yet not an adult either. He could see a pediatrician for another year, or he could see a doctor who might not understand adolescence. In addition, we live in a small town with limited access to specialists. To overcome the hurdles, we spent six months driving to UAB, Emory University and the Mayo Clinic in search of care. Next, we faced financial hurdles. Our insurance company charged us $600 a month for intravenous IG (IVIG), and Connor had a difficult time with side effects. After four months, we switched him to subcutaneous IG (SCIG), and our insurance company lowered our out-of-pocket cost to $35 per month. SCIG is perfect for Connor; it gives him control over his treatment.

**IG Living:** Connor is now a young adult. How have you transitioned the management of his care?

**Kelley:** A year and a half after his diagnosis, Connor moved into a dorm at Florida Atlantic University (FAU) 10 hours away. His doctor at UAB recommended an immunology practice near his college, and that was the first place we visited after moving him. For the first two years of college, I attended his doctor appointments at the beginning and end of the year with him. For the appointments in between, I would talk to him before each one to discuss questions or concerns he had. After the second year, he went to all of the appointments by himself. By the end of his second year of college, we made another decision to place him in control of ordering his medicine and communicating with the insurance company. When mistakes have been made with an order, I have him talk to the insurance representatives. It was important to us to make him coordinate all of his care by the time he turned 20.

**IG Living:** Connor’s athletic and academic accomplishments are impressive. How does he juggle these accomplishments while living with CVID?

**Kelley:** Before Connor left for college, I had each of his doctors talk to him about drinking and drugs. I knew the temptations would be present in college, and I also knew he needed to hear it from someone other than me. He left for college understanding he needed to follow his treatment plan and that the consequences of not following the plan could end his dream of swimming in college and earning a degree in electrical engineering. It was hard because I worried about everything from dirty door knobs to him not taking a sore throat or the flu seriously. Within the first year of college, we felt confident he would follow his treatment plan and see his doctors if he wasn’t feeling well. With swimming, he had to travel throughout the school year. He would plan his infusions around that schedule. His coaches knew he had CVID and were very supportive.

**IG Living:** What advice do you have for other parents?

**Kelley:** Find the best doctors who specialize in your child’s diagnosis, and share your story. I have learned so much from others by sharing our story, and I have been able to help others. I have shared the list of doctors Dr. Harville gave me with multiple families in similar situations. I also read all of the literature the Immune Deficiency Foundation sends us.

**IG Living:** Connor, what has this journey with chronic illness taught you?

**Connor:** I learned to never give up. I also try to appreciate everything.

**IG Living:** Has having CVID impacted your personal and social life?

**Connor:** One of my favorite parts of college was being on the FAU swim and dive team. I don’t feel like having CVID impacted my social life or my ability to be a part of the team. I am able to do everything I want to do.

**IG Living:** What advice do you have for other teens/young adults?

**Connor:** I would tell them to focus on the areas of their life over which they have control and continue with their normal activities as much as possible. I can control my sleep, the food I eat and the way I think. When I was first diagnosed, this helped me to stay focused and continue with school and swimming.

**IG Living:** What are your goals for the future?

**Connor:** I would like to continue my education and pursue a master’s degree in electrical engineering.

**Trudie Mitschang** is a contributing writer for IG Living magazine.
Chasing the Dream
By Stacey Philpot

LAST YEAR, I decided it was finally time to do something I’d been dreaming of for 10 years or more: It was time to pursue my master’s degree. It wasn’t that my health had reached some miraculous state of unexpected stability, or that money had fallen from the sky. No monstrously large hand had appeared from above and written the words “It’s time” across the wall. I merely made a decision based on a vague sense of inner-knowing and a great deal of research. And, then, I took the leap. Perhaps you’ve been pondering a similar leap. If so, here are three things I’ve learned from my journey thus far:

I’d know I tried. If I couldn’t balance my classes and my health, there was no shame in that. Maybe I could try again at a later time. If my brain couldn’t process the high-level materials, or if I received failing grades on my papers and exams, I’d celebrate the effort I put into the process and move forward. We might not be capable of achieving all we want at this moment, but we won’t know until we try. We might surprise ourselves.

2) Ask for what you need. Do you need accommodations at work or support from friends to take the next step? Don’t be afraid to ask. Know your rights, and advocate for yourself. Some of us feel bad asking for help, and others don’t want to rock the boat, but we are worth it! For me, this may mean setting aside time to study, asking for help around the house or fighting for accommodations on campus. Whatever it looks like for you, don’t be afraid to ask for what you need.

3) Chase the dream. Perhaps the dream will change shape again and again before it materializes. Maybe it will be delayed over and over again by the many obstacles we face. But the very same obstacles that threaten to thwart us from crossing the finish line can also be the fuel that keeps us going. I have yearned to be a counselor since I was a young girl. But now, the desire to come alongside those who know the pain of chronic illness and to say “You are seen. You are known. You are not alone” is more significant than I could have ever imagined. Now, the dream is fueled by the desire to come alongside others experiencing the pain I’ve known. Chase the dream. Let your pain and your obstacles become fuel on the days it feels impossible.

For now, I have to work much harder than my school counterparts while attempting to balance my health. Sometimes, that means I write a paper while infusing, or I read textbooks while waiting to see a new doctor. I don’t know what chasing the dream will look like for you, how many years it will take, how much harder you will have to work or how many times it may be derailed, but I do know your dreams still matter. You are seen. You are known. You are not alone. And, your dreams are worth chasing. It just might be time.

Contrary to what every inspirational poster has told us since middle school, we may not be able to accomplish all we set our minds to, and that’s OK.

1) Make room for failure. Contrary to what every inspirational poster has told us since middle school, we may not be able to accomplish all we set our minds to, and that’s OK. Just because we may sometimes fail, that doesn’t make us a failure. I decided from the moment I enrolled in my classes it would be perfectly acceptable to fail as long as I gave it my all. If I didn’t get accepted into the program, I would be disappointed, but at least

STACEY PHILPOT is an author, gootball and avid reader. You can find her blog at chronicallywhole.com, where she shares her journey of making the most of a life touched by common variable immunodeficiency, Lyme disease and rheumatoid arthritis.
**Work in Progress: Mental Health Help with Chronic Illness**

By Ilana Jacqueline

I HAVE A confession to make: I see a therapist. Actually, I’ve seen a lot of therapists throughout my life. And, it’s something I don’t often talk publicly about. For so long, my doctors blamed my symptoms on my mental health and didn’t investigate their physical root cause. A delayed diagnosis due to skepticism is certainly a sore spot for me, and it’s something I’m working on accepting with the help of a psychologist. For so long, I felt ashamed of the way people in my life perceived my illness and the way I perceived it. I also felt shame about treatment choices I made, and my inability to balance my career, social life, relationship and self-esteem with a chronic disease. And, I’m still a work in progress.

At times, therapy wasn’t helpful for me, so it made me not want to go back. But, I needed to. That’s because depression and anxiety are only natural when your life is full of hospitalizations, doctor appointments, nerve-wrecking medical decisions and a general lack of understanding by the people around you.

If you’ve struggled with the idea of going to therapy, or the idea of going back to therapy after a bad experience, here are some tips I hope will help:

1) Pick the right kind of therapy for you. There are so many different kinds of therapists and therapy methods out there! There are therapists who will dive deep into your childhood to try to help you understand how your past experiences have impacted your current life choices. There are therapists who help you modify your behavior by walking through your intentions and hopes for the future to help you to set and stay on top of your goals. There are life coaches who give constructive advice on how to improve different areas of your life. There are religious confidants like priests and rabbis who will bring spiritual elements into your therapy. You may think you need one type of therapy, but after several sessions, you may discover that isn’t the method for you. Don’t give up! Sometimes you have to figure out what doesn’t work before you figure out what does.

2) Know your benefits. If the cost of therapy is a burden you can’t overcome, know that you have options. Under many insurance plans, psychologists are covered just as any other specialist might be. Your co-pay could be low to nonexistent if you’ve already met your deductible. If the cost is still too high, your therapist might offer sessions on a sliding scale according to your income. You just need to ask. They may be able to reduce your fee per session to something that fits your budget better. If you have absolutely no money to spare on your mental health, many religious institutions such as churches, temples or local religious community centers offer mental health services free of charge.

3) Speak up about your needs. It’s important to make it clear in your first session what exactly it is you’re looking to accomplish. Don’t be afraid to say: “I don’t need sympathy. I need tough love!” (Or the opposite, if it suits you!) Ask if your therapist has any familiarity with patients who have chronic illness or who are going through other unique struggles like the ones you’re dealing with. And, if the session is getting off track, or if you feel it isn’t a fit for you, move on. It’s OK to get to a second, third or eighth attempt before you find the right fit for your needs. This is your time. Make the most of it!

And, most of all, make one of your main goals to remember your mental health is worth an hour or two a week. You deserve to feel well in every way you possibly can!
CHILDREN WITH chronic illness are just like any other kids. They attend school, participate in sports and enjoy spending time with their friends. As parents of chronically ill kids, we want them to have these experiences in order to live a full and well-rounded life. And for that to happen, they can’t always be with us. Sometimes, we have to hand them over to the care of another adult, and in many cases, the parent of one of our children’s friends. But, because of their condition, to keep them safe and healthy, we have to share information about our children’s health condition with their friends’ parents. In these situations, how much should we share, and how do we go about it?

Prepare ahead of time. If you feel the need to discuss your child’s health condition with another parent, particularly the parent of your child’s friend, take time to think through what you want to say beforehand, and then make plans to get together and discuss it.

My oldest son, who has a primary immunodeficiency disease, will be going on a camping trip with a friend and his parents, and three other boys. I will have to explain his condition in detail, since they will be far from medical care, spending several days in the woods where ticks and mosquitos are abundant. I plan to ask his friend’s parents to make sure my son takes precautions such as conducting frequent tick checks and using bug spray. If these parents understand why I’m concerned, they’ll probably be more likely to take my requests seriously.

There have been times, I’m afraid to say, I have shared about my son’s health condition with other moms in a more frantic manner, and I’m pretty sure they thought I was crazy. Perhaps another mom tried to downplay my son’s condition, or tried to tell me I was “overreacting” under certain circumstances. In these situations, when I’m on the defensive, my words tend to come out in an emotionally charged, rant-style retort, rather than in a calm, well-thought-out, intelligent discussion. It happens sometimes. As parents, we take our child’s health condition very personally, and sometimes we can become offended by other parents, even our own well-meaning friends, who just don’t understand.

So to assure you’re taken seriously, it’s probably best to practice what you’d like to say ahead of time. This is especially helpful if the thought of sharing information about your child’s condition makes you nervous, or if you’re concerned about how other parents might react. Practice in front of a relative or a close friend, and ask for their feedback.

When sharing with your child’s friends and their parents, be aware they might have questions. A good way to prepare for that is to research information about your child’s diagnosis so you can respond to their questions appropriately. When you are prepared, you will come across more at ease and relaxed. This will go a long way if you want others to actually hear what you’re saying. People generally tune out someone who is speaking while in a state of heightened emotion.

Share your child’s unique story. When sharing about your child’s condition, it may be easier to tell it like a story rather than fact-spewing. You may want to share any struggles he or she has experienced and/or overcome, and any joys and milestones he or she has reached. This will make the listener
more receptive to your message, as though they’re being brought along on your journey, rather than being lectured. Not many people are sympathetic to a “do this/don’t do that” speech. And remember to use laymen’s terms. While you are familiar with the medical terminology surrounding your child’s medical condition, his or her friend’s parents may not be. Try to use words most people can comprehend.\(^1\)

Share what you want, when you want. What parents say about their child’s condition and how much they share is up to them and the child. There are no rules for how much information to divulge. While some children and teens feel comfortable with their condition and feel free to share details and spread awareness, others may be more inhibited and prefer to keep the details of their condition private.

My oldest son is more private when it comes to his immune deficiency. This might be because he is almost 16 and his image is important to him. Some things, such as the fact that he receives weekly subcutaneous immune globulin infusions, his friends know. Other things, like his lung disease and daily chest physiotherapy, he keeps to himself. If a friend spends the night at our house, he may choose not to do therapy with his VEST until after his friend leaves. I let him make that decision instead of embarrassing him, because I realize it is his condition, not mine, and I don’t truly know how it feels to be him.

As parents, we should be sure our children are comfortable with what we are sharing with their friends and their families. It’s a good idea to check with kids before having a conversation that is specifically about their health. Involve them in the discussion by saying things such as, “Before you spend the night at Johnny’s house, I would like to talk with his mom about your condition. Would that be OK with you? What do you think we should say? Is there anything you don’t want me to share?” There’s no law that says if your child has a diagnosis, you must share it with the world.\(^1\) Disclose only those things you feel will help your child, and keep other details to yourself.

When sharing about your child’s condition, it may be easier to tell it like a story rather than fact-spewing.

Don’t expect full understanding after one conversation. Tasra Dawson, who suffers from an “invisible” chronic illness, is creating a documentary about invisible illnesses to help people feel they are not alone. When it comes to sharing the details of chronic illness to others, she gives this advice: “Don’t feel like you have to give the play-by-play of how you got to where you are. Start small so that people have time to process what you’re sharing. You didn’t learn all you know in one overwhelming moment, it was doled out in diagnosis after diagnosis, appointments, doctors, research, books and so many other ways over time. Give loved ones that same chance to absorb the information and respond in kind.”\(^2\) This same advice applies to parents when speaking to others about their child’s condition. Explaining in abundant detail can overwhelm one listening, especially if the details are medical in nature. Taking Dawson’s advice, parents should touch on the main points in their first discussion with friends and their families, and then add more details with subsequent discussions, allowing the details to sink in over time.

And, remember while you are sharing about your child’s condition, you are also modeling what it means to build open, trusting relationships with others. It takes courage to talk about personal struggles and to share your child’s vulnerabilities, as well as some of your own insecurities and fears. But by doing so, you show your children it’s better to invite others into their lives, even the parts that might be different from everyone else’s, rather than cutting themselves off from relationships to suffer in private.\(^2\)

References

Jessica Leigh Johnson is a stay-at-home mom and mother of four kids, three of whom have X-linked agammaglobulinemia. She is a member of American Christian Fiction Writers and has written one book about the loss of her son to a primary immunodeficiency.
Sleep Disorders: When Counting Sheep Isn’t Enough

By Heather Bremner Claverie

CATCHING ZZZ’S is not always easy. Between 50 million and 70 million U.S. adults report having some sort of sleep disorder, according to the American Sleep Association. And, of those millions of sleep-deprived Americans, a total of 48 percent reported snoring, 37.9 percent said they unintentionally fell asleep during the day and 4.7 percent admitted to dozing off while driving.

When an individual has a difficult time falling asleep, staying asleep or doesn’t get quality sleep, a sleep disorder may be the root cause. Sleep disorders are a diverse lot. Ailments can range from restless leg syndrome and narcolepsy to obstructive sleep apnea and insomnia.

Although the amount of sleep one needs varies, most adults require between seven hours and nine hours every night, according to the National Sleep Foundation. So, what happens when those hours aren’t met? Since sleep is critical to humans for both mental and physical health, a lack of it is linked to a myriad of issues. Mental health conditions, heart problems, difficulty concentrating, depression, weight problems and even a shorter life expectancy are some of the issues linked to sleep deprivation. And, nodding off behind the wheel is one of the most dangerous outcomes of sleep deprivation. The American Sleep Association says drowsy driving is responsible for 1,550 fatalities and 40,000 nonfatal injuries annually.

Sleep apnea, a disorder characterized by repetitive breathing pauses during sleep, can serve as the root cause of sleepiness. This condition can lead to a decrease in blood-oxygen levels that may cause individuals to wake up momentarily and gasp. Although they may have had the disorder for years, many people with sleep apnea have no idea they suffer from it until they’re diagnosed.

Insomnia is another common sleep disorder. When daily pressures start swirling through people’s heads, many find it difficult to fall or stay asleep. Although healthcare providers can’t always pinpoint the actual cause of insomnia, there are certain factors that can lead to restlessness. Primary insomnia can be caused by physical or emotional stress, or a dramatic schedule change such as a new baby or jet lag. But when secondary insomnia enters the picture, the source becomes more complicated. Restless leg syndrome, depression, anxiety, caffeine or alcohol may be the culprit.

Snuggle up to this good news: Sleep disorders are curable. Obstructive sleep apnea is often triggered by obesity, which means dropping some of that extra weight may reverse the condition. In addition, smoking, excessive drinking and drug use can all cause the tissues in the airways to relax and become blocked. Continuous positive airway pressure (CPAP) therapy is one of the most common and effective treatments for sleep apnea. The CPAP machine, which is attached to a mask that fits into the nose, is worn during sleep and keeps the airways open by applying mild air pressure.

Since insomnia can be caused by a variety of factors, treatments also vary. Individuals suffering from anxiety or depression may find they can sleep after taking certain medications. And, while some physicians may prescribe sleep medications, these are usually just a temporary fix. Sleep therapy, cognitive behavior therapy, relaxation techniques and/or avoiding stimulants and alcohol may also help. In addition, simple changes such as revamping sleeping environments or eliminating sleep-zapping distractions from the bedroom may help alleviate insomnia.

In today’s distraction-inducing society, a good night’s sleep isn’t necessarily something that comes naturally. Turning off the smart phone, diffusing some lavender and opening up a good book before turning in may be just the right recipe for some good old beauty sleep.

HEATHER BREMNER CLAVERIE is a contributing writer for IG Living magazine.
Since the most common and effective treatment for obstructive sleep apnea involves wearing a continuous positive airway pressure (CPAP) mask, the market is filled with these devices. Yet, not all CPAP masks are equal. Noise level, fit, cost, size, effectiveness and smart options are some factors that many patients consider when making a choice. The ResMed AirSense 10 AutoSet appears to check all of those boxes. This compact CPAP is equipped with a built-in heated humidifier, runs quietly, tracks sleep and even has a special version for women. $885; [www.cpap.com](http://www.cpap.com)

### Stick on Sleep

A little melatonin can go a long way in the face of sleep disorders. Nite Nite Patches are transdermal patches designed to help induce sleep. Stick on the all-natural patches and wait for the body to slowly and evenly absorb the therapeutic combination of melatonin, hops and valerian root. What’s great is the body absorbs it over a 12-hour period, and it doesn’t involve taking pills. $12 for eight patches; [www.uncommongoods.com](http://www.uncommongoods.com)

### Spray on Sleep

Ready for that long-covered beauty sleep? This Works Deep Sleep Spray combination of lavender, vetiver and wild chamomile oils is designed to help ease anxiety and induce sleep faster. Spritz the calming fragrance onto some pillows and fall into a deep slumber. This spray is suitable to use during pregnancy. $29; [www.dermstore.com](http://www.dermstore.com)

### Sleep Soundly

Cuddling up to a pillow that emits white noise? Sounds like music to the ears of insomniacs. The PILO Classic Ergonomic Smart Music Pillow has made this a reality. The rock-shaped memory foam pillow has built-in sound speakers and connects to a sound sleep-aide app. The curved structure was designed to cradle the neck and head. In addition, the sleep-inducing pillow comes with a washable cotton case. $169; [www.amazon.com](http://www.amazon.com)

### Shopping Guide to Sleep Aids

### Regenerating Jammies

Although people spend at least eight hours a day sleeping, for many women, what they wear to bed is an afterthought. Old T-shirts, yoga pants or sweats are often thrown on. Yet, soft, durable and comfortable pajamas can help restore and recharge during the wee hours. Lunya pieces are designed with fabrics that increase blood flow while sleeping. The stylish sleepwear won’t ride up, and has pockets that lay flat and straps that stay put. Prices vary; [www.lunya.co](http://www.lunya.co)

### Weighted Down

Heavy blankets have been shown to help with sleep, so why not eye masks, too? The NodPod weighted sleep mask blocks out light while creating perfect conditions for snoozing away. The mask is snap- and strap-free and can also be chilled for headache or puffy eye relief. It molds to the contours of the face and is machine washable. $29.95; [www.thegrommet.com/nodpod-travel-weighted-eye-pillow](http://www.thegrommet.com/nodpod-travel-weighted-eye-pillow)
Alise Gilley began her struggle with chronic illness in late elementary school. It took years to diagnose and has altered every facet of her life. The hardest and most shameful part of the illness came when she began to battle with the mental side of the illness. After years of thinking something was wrong spiritually, she finally found the right people to walk with her to live the best life possible fighting chronic and mental illness. She wrote this book for those who are battling with their bodies and to encourage them to keep pushing until they get answers.

How do you live well when the physical foundation of your life is crumbling? This is the challenge for millions who live with diseases for which there is no cure. These incurable ailments produce a life of constant pain, fatigue, numbness, dizziness and other debilitating symptoms that create chronic suffering. Can you thrive in life while experiencing the suffering persistent sickness provokes? In When There Is No Cure, Dr. Svensson guides readers to a path of thriving when life’s journey includes an incurable ailment. Drawing on his expertise as a pharmacist-scientist, as well as a fellow sufferer with several incurable diseases, he helps patients steer through the twists and turns of life with chronic illness.

Throughout Elderhood, physician and author Louise Aronson, a Harvard-trained geriatrician, shares anecdotes from her 25 years of caring for patients, and from her personal experiences of getting older and watching her parents age. From what these experiences have taught her, she envisions a large-scale shift in society’s — and medicine’s — attitude toward aging, made up of crucial adjustments in how we see the changes in each other’s and our own bodies, how we care for older people, how we set doctors’ salaries and bill patients and, ultimately, how we conceive of the final third of life — not as an ending or decline, but as yet another stage of life with its hardships and challenges, opportunities and joys.
“You can lament what is lost to you, whether it’s opportunity, a person or your health, but clinging to anger is no way to experience life.” — Rebecca Zook in “Life Lessons,” excerpted from Chronic Inspiration.

Download a daily dose of inspiration with this heartfelt compilation of writings on life with chronic illness. From coping strategies and parenting tips to “from the trenches” advice on dealing with family and friends who simply don’t get it, these personal stories are sure to uplift, challenge and inspire. Honest and candid, Chronic Inspiration: Heartfelt Perspectives on Life with Chronic Illness gives voice to those who refuse to let their diagnosis define who they are or what they can accomplish.

“For the patient community, this was invaluable. When I downloaded it, I knew this would be something I would refer to over and over again.”

— Jenny Gardner

Chronic Inspiration can be purchased on iTunes, Amazon and Barnes and Noble.com
**Ataxia Telangiectasia (A-T)**
- **WEBSITES**
  - A-T Children’s Project: www.atcp.org

**Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)**
- **WEBSITES**
  - GBS/CIDP Foundation International: www.gbs-cidp.org
  - The Foundation for Peripheral Neuropathy: www.foundationforpn.com

**Evans Syndrome**
- **ONLINE PEER SUPPORT**
  - Evans Syndrome Research and Support Group: www.evanssyndrome.org

**Guillain-Barré Syndrome (GBS)**
- **WEBSITES**
  - GBS/CIDP Foundation International: www.gbs-cidp.org
  - The Foundation for Peripheral Neuropathy: www.foundationforpn.com

**Idiopathic Thrombocytopenic Purpura (ITP)**
- **WEBSITES**
  - ITP Support Association – UK: www.itpsupport.org.uk
  - Platelet Disorder Support Association: www.pdsa.org

**Kawasaki Disease**
- **WEBSITES**
  - American Heart Association: www.heart.org/HEARTORG/Conditions/Heart-Conditions/Kawasaki-Disease_UCM_308677_Article.jsp#T1172bfb0PWE0
  - Kawasaki Disease Foundation: www.kdfoundation.org
  - KidsHealth: kidshealth.org/parent/medical/heart/kawasaki.html

**Mitochondrial Disease**
- **WEBSITES**
  - United Mitochondrial Disease Foundation: www.umdf.org
  - MitoAction: www.mitaction.org

**Multifocal Motor Neuropathy (MMN)**
- **WEBSITES**
  - The Foundation for Peripheral Neuropathy: www.foundationforpn.com

**Multiple Sclerosis (MS)**
- **WEB/TIES**
  - All About Multiple Sclerosis: www.mult-sclerosis.org/index.html
  - Multiple Sclerosis Association of America: mymsaaa.org
  - Multiple Sclerosis Foundation: www.msfocus.org
  - National Multiple Sclerosis Society: www.nationalmsociety.org

**Multiple Sclerosis and Chat Rooms**
- **ONLINE PEER SUPPORT**
  - Friends with MS: www.FriendsWithMS.com
  - MSWorld’s Chat and Message Board: www.msworld.org

**Myasthenia Gravis (MG)**
- **WEB/TIES**
  - Myasthenia Gravis Foundation of America (MGFA): www.myasthenia.org
  - Genetic Alliance: www.geneticalliance.org

**Myositis**
- **WEB/TIES**
  - The Myositis Association: www.myositis.org
  - International Myositis Assessment and Clinical Studies Group: www.nichd.nih.gov/research/resources/imacs

**Myositis Support Group – UK**
  - www.myositis.org.uk

**Peripheral Neuropathy (PN)**
- **WEB/TIES**
  - Peripheral neuropathy Action Foundation: www.neuropathyaction.org
  - Western Neuropathy Association: www.prnhelp.org
  - Neuropathy Alliance of Texas: neuropathyallianceoftx.org
  - The Foundation for Peripheral Neuropathy: www.foundationforpn.com

**Primary Immune Deficiency Disease (PI)**
- **WEB/TIES**
  - Immune Deficiency Foundation: www.primaryimmune.org
  - Jeffrey Modell Foundation: www.info4pi.org
  - The National Institute of Child Health and Human Development (NICHD): www.nichd.nih.gov/Pages/index.aspx
  - American Academy of Allergy, Asthma & Immunology: www.aaaai.org
  - International Patient Organisation for Primary Immunodeficiencies (IPOD) — UK: www.ipodi.org
  - New England Primary Immunodeficiency Network: www.nepin.org
  - Rainbow Allergy-Immunology: www.uhospitals.org/rainbow/services/allergy-immunology

**ONLINE PEER SUPPORT**
- IDF Friends: www.idffriends.com
- Jeffrey Modell Foundation Facebook Page: www.facebook.com/JMFworld
- IDF Peer Support Program: www.primaryimmune.org/idf-peer-support-program

**Scleroderma**
- **WEB/TIES**
  - Scleroderma Foundation: www.scleroderma.org
  - Scleroderma Research Foundation: www.sfrcure.org
  - Johns Hopkins Scleroderma Center: www.hopkinscscleroderma.org

**ONLINE PEER SUPPORT**
- International Scleroderma Network: www.sclero.org/support/forums/a-to-z.html

**Scleroderma Foundation**
  - www.scleroderma.org
  - www.sfrcure.org
  - www.hopkinscscleroderma.org

**Stiff Person Syndrome (SPS)**
- **WEB/TIES**
  - American Autoimmune Related Diseases Association Inc.: www.aarda.org
  - Genetic Alliance: www.geneticalliance.org
  - Living with Stiff Person Syndrome (personal account): www.livingwithspss.com
  - Stiff Person Syndrome: www.stiffpersongrid.net

**Stiff Person Syndrome (SPS)**
- **WEBSITES**
  - Stiff Person Syndrome: www.stiffpersonsyndrome.net
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- Shortcuts to frequently purchased products
- FFF Sales Team contact information
- Detailed product pages
- Product alternatives if products are back-ordered or unavailable
- Convenience and accessibility to drop-ship products
- Shopping Cart feature displays account number and shipping address to minimize purchasing errors
- My Favorites feature for frequently ordered products
- BioVision reporting tool provides analysis of purchasing patterns

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